# A phenomenological approach to understanding the psychological response to chronic low back pain

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I dedicate this paper to my supervisor, teacher, and friend Dr. Jarold Cosby. Your unconditional support and positive encouragement of my work was more important than you could ever imagine.

I also dedicate this paper to my family; my mother Nicolene, my father Robert, and my brothers Stephen and Philip. You all helped to turn our basement into my own personal writing sanctuary and you all made sacrifices to benefit my writing. For this I am forever in gratitude.

**Abstract**

Chronic low back pain (CLBP) is a complex health problem of psychological manifestations not fully understood. Using interpretive phenomenological analysis, 11 semi-structured interviews were conducted to help understand the meaning of the lived experience of CLBP; focusing on the psychological response to pain and the role of depression, catastrophizing, fear-avoidance behavior, anxiety and somatization. Participants characterized CLBP as persistent tolerable low back pain (TLBP) interrupted by periods of intolerable low back pain (ILBP). ILBP contributed to recurring bouts of helplessness, depression, frustration with the medical system and increased fear based on the perceived consequences of anticipated recurrences, all of which were mediated by the uncertainty of such pain. During times of TLBP all participants pursued a permanent pain consciousness as they felt susceptible to experience a recurrence. As CLBP progressed, participants felt they were living with a weakness, became isolated from those without CLBP and integrated pain into their self-concept.

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## Chapter 1 – Introduction

Low back pain (LBP)[1] is a ubiquitous health problem as 60-85% of people in western countries will experience an episode of LBP at some point in their lifetime (Papageorgiou, Croft, Ferry, Jayson, & Silman, 1995; Harreby, Kjer, Hesselsoe, & Neergaard, 1996; Hillman, Wright, Rajaratnam, Tennant, & Chamberlain, 1996; Cassidy, Carroll, & Cote, 1998; Trainor & Wiesel, 2002). Estimates of direct health care expenditures among individuals with LBP in the United States reached $90.7 billion in 1998 (Luo, Pietrobon, Sun, Liu, & Hey, 2004) and LBP is the largest single cause of absence from work in the UK, accounting for over £11 billion in direct and indirect costs in 2000 (Maniadakis & Gray, 2000). Research has shown that an average of 24% to 50% of patients who experience LBP will continue to have symptoms 12 months later (Gureje et al., 2001; Stanton et al., 2008) and that the annual prevalence of chronic low back pain (CLBP) ranges from 15% to 45%, with a point prevalence[2] of 30% (Sternbach, 1986; Anderson et al., 1992; Lawrence, Helmick, & Arnett, 1998; Cassidy, Carroll, & Côté, 1998; Manchikanti, 2000; Deyo, Mirza, & Martin, 2006). However, it is difficult to assess the prevalence of CLBP due to varying definitions of such pain and a lack of general consensus over how it develops (Manchikanti, Singh, Datta, Cohen, & Hirsch, 2009; Dunn & Croft, 2004; van Tulder et al., 2002b). Historically, LBP conceptualizations have been dominated by the biomedical model in which pain is proportional to identified pathology (e.g.

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[1] Low back pain is usually defined as pain, muscle tension, or stiffness localized below the costal margin and above the inferior gluteal folds, with out without leg pain (van Tulder, & Koes, 2002b).
[2] This is the proportion of the population at issue that experience CLBP at a particular point in time (van et al., 2002b).

tissue damage) (Turk, 1990; Turk & Monarch, 2002a). However, the disabling nature of CLBP stems from somatic, psychological, and social factors (Waddell, 1987; Turk, 1990; Schultz et al., 2002) and contemporary cognitive–behavioral models portray the condition as a sensory-affective response involving physiological, cognitive, and behavioral components (Waddell, 1987; Vlaeyen & Crombez 1999; Burton, Waddell, Tillotson, & Summerton, 1999; Turk et al., 2002a). It is widely believed that psychological factors are associated with the onset of CLBP and may be stronger predictors for the risk of developing long term pain and disability than biomedical factors (Hasenbring, Hallner, & Klassen, 2002). Furthermore, a number of researchers have concluded that psychological factors are highly connected with the development, maintenance, and frequency of CLBP, specifically depression, catastrophizing, fear-avoidance behavior, anxiety, and somatization (Linton 2000; Hasenbring et al., 2001; Pincus, Burton, Vogel, & Field, 2002; Dunn et al., 2004; Manchikanti et al., 2009).

In light of the abundance of recent literature, the psychological response to CLBP is still somewhat ambiguous. This is evidenced by clinical mismanagement, as only 15 % of patients with spinal pain receive a definitive diagnosis (Murphy et al., 2007) and by research on the efficacy of psychological intervention on CLBP.[3] Using the Cochrane review system, van Tulder et al. (2001) found behavioral interventions (i.e., operant, cognitive, and respondent) to be generally indistinguishable from one another, of no incremental benefit when added to usual care (e.g. physiotherapy) and moderately superior to no treatment, placebo, and wait-list controls. A systematic

[3] Psychological interventions for CLBP have become common alternatives to traditional medical and rehabilitation approaches (Nielson & Weir, 2001; Smith & Gribbin, 2001).

review by Nielson and Weir (2001) found that multimodal biopsychosocial approaches which include cognitive-behavioral and/or behavioral components were effective for treating short term (12 months) but not longer term LBP. There have been additional reviews which advocate the efficacy of psychological intervention in comparison to traditional medical rehabilitation approaches to CLBP (Morley, Eccleston, & Williams, 1999; Guzman et al., 2001; Hoffman, Papas, Chatkoff, & Kerns, 2007). However, these reviews also perpetuate the need for an improved understanding of the psychological response to CLBP. For example, a meta-analysis by Morley et al. (1999) found cognitive behavioral treatment (behavior therapy, biofeedback and relaxation) to be effective when compared with active treatment controls (e.g. pain clinic treatment, physiotherapy, occupational therapy). However, differences in mood/affect (depression and anxiety) negative cognitive coping and appraisal (e.g. catastrophizing) and social role functioning were not significant. A review of multidisciplinary biopsychosocial rehabilitation in patients with CLBP by Guzman et al. (2001) found that while intensive (> 100 hours), daily multidisciplinary biopsychosocial rehabilitation[4] with a functional restoration approach[5] improved pain and function, only one trial reported positive effects on quality of life. Finally, a meta-analysis by Hoffman et al. (2007) provided support for the efficacy of cognitive behavioral, self regulatory and multidisciplinary psychological interventions in reducing self-reported pain, pain-related interference, disability, and increasing health

[4] a minimum of the physical dimension (e.g. physiotherapy) and at least one of the other psychological, social or occupational dimensions (e.g. psychological counseling) had to be present as defined by Guzman et al.(1998) protocol of multidisciplinary team approaches for the treatment of CLBP.

[5] As advocated by Mayer et al., 1988, which refers to specific exercises, training in functional tasks, education, and work simulation/hardening. This treatment is guided by repeated testing, with an emphasis on feeding progress data back to the patient to enhance spinal mobility and strength.

related quality of life among persons with CLBP. However, these interventions had inconsistent effects on emotional functioning scores and these researchers recommended enhancing psychological interventions through addressing the putative mechanisms they identified to be involved in the development and perpetuation of CLBP, such as pain catastrophizing (Sullivan, Rouse, Bishop, & Johnston, 1997) fear-avoidance (Vlaeyen & Linton, 2000) depression (Banks & Kerns, 1996) and pain relevant communications (Kerns, Haythornthwaite, Southwick, & Giller, 1990).

Psychological research has traditionally relied on positivistic approaches to inquiry (Smith, 1996). Chronic pain literature is no different, as psychological CLBP literature is largely constructed within the philosophical tradition of quantitative research, emphasizing questionnaire and survey studies (Linton, 2000; Hasenbring et al., 2001; Pincus, Burton, Vogel, & Field, 2002; Van Tulder et al., 2001; Dunn et al., 2004; Hoffman et al., 2007). However, methodological and philosophical traditions can become methodological and philosophical limitations. For example, cognitive research examining the relationship between a psychological factor (e.g. depression) and CLBP will typically endorse cross sectional designs to measure outcomes associated with chronic illness (Linton, 2000; Hasenbring et al., 2001; Pincus et al., 2002). Such a research design fails to determine with certainty which variable is the cause and which variable is the effect, as it can only show two variables to be "associated" with one another at one specific point in time (Shadish, Cook, & Campbell, 2002). These limitations perpetuate the failure of psychological CLBP research to adequately determine whether psychological change precedes chronic illness or vice versa (Gatchel, 1996; Dunn et al., 2004). More recently, quantitative

researchers have began to investigate the role of psychological factors in CLBP with prospective study designs due to their increased ability to determine which psychological factors are casually related to increased pain (Linton, 2002; Dunn et al., 2004). Although prospective researchers can indicate direction of causality, they cannot fully explain how such cause and effect actually works. Furthermore, cross-sectional and prospective studies alike rely on standardized methodologies and psychometric scales to evaluate change and such scales fail to determine the experience and meaning of an illness from the viewpoint of the individual experiencing it (Bilsbury & Richman, 2002).

Qualitative interviews allow the researcher the opportunity to incorporate each patient's unique account of their illness experience. This is essential as patient beliefs are important for describing and understanding illness and they provide a missing link between the biomedical and psychosocial systems (Aylward, 2006). Furthermore, qualitative research is a useful approach for exploring perplexing clinical situations (Beaton & Clark 2009) and as Menzel and Robinson (2006) explain, CLBP is an intricate and complex illness: "Musculoskeletal disorders are associated with pain. Pain has sensory, affective, and cognitive dimensions and its clinical assessment is through subjective reports" (p. 61). Therefore, a subjective and qualitative approach is an appropriate method for understanding the psychological complexities of CLBP. Interpretive phenomenological analysis (IPA) (Smith & Osborn, 2003) characterizes such an approach, as it is a qualitative research method concerned with understanding human behavior through the subjective perceptions (expressed via interview) of those experiencing such phenomena (Willis, 2007). Furthermore, IPA aims to explore each

participant's personal world in an attempt to determine the meanings of particular experiences (Smith et al., 2003). The psychological reaction to CLBP is a highly personal experience, and thus, IPA is a logical method for such investigation. Therefore, the purpose of this study is to determine the meaning of the lived experiences of CLBP patients, in an attempt to understand the psychological reaction to CLBP using IPA. While identifying depression, catastrophizing, fear-avoidance behavior, anxiety, and somatization (Linton 2000; Hasenbring et al., 2001; Pincus, Burton, Vogel, & Field, 2002; Dunn et al., 2004) as psychological research themes,[6] the study will look to answer two research questions; 1. How do participants psychologically respond to CLBP? 2. How are depression, catastrophizing, fear-avoidance behavior, anxiety, and somatization (Linton, 2000; Hasenbring et al., 2001; Pincus, Burton, Vogel, & Field, 2002; Dunn et al., 2004) implicated in their response?

[6] In this case, "psychological research themes" represent what qualitative researchers would typically recognize as sensitizing concepts; categories the researcher brings to the data which establish a general sense of reference for the researcher during the interview process (Patton, 2002).

## Chapter 2 – Review of Literature

### The Psychological Research Themes

Although there have been some contemporary reviews of psychological interventions for treating CLBP (Van Tulder at al., 2001; Hoffman et al., 2007), there have been few systematic reviews on the psychological connection to CLBP. Steven Linton was the first to conduct a systematic analysis of well-controlled prospective studies dating back to 1967; the review included 37 studies. Linton (2000) found that anxiety, stress, mood (depression) and emotions, and cognitive functioning (fear-avoidance and catastrophizing) not only played a significant role in chronic pain but in acute pain as well; particularly in the transfer from acute low back pain (ALBP) to CLBP[7]. A year later Hasenbring et al. (2001) used a grading system similar to that of Linton's (2000) to systematically select and analyze 37 good-quality perspective studies examining the role of psychological risk factors in the onset and development of CLBP. They found depression to be associated with the onset of pain, while depression and pain related cognitions (fear-avoidance and catastrophizing) were clearly linked in the transition from acute to chronic pain. A systematic review by Pincus et al. (2002) was the first of its kind to specifically examine the psychological factors contributing to the transition from acute to chronic LBP. They found that depression, somatization, and to a lesser extent catastrophizng were all involved in the transition.

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[7] Gatchel (1996) developed a three-stage conceptual model on the transition from acute pain to chronic pain, disability and accompanying psychosocial distress.

Although no one review incorporated all five of the psychological research themes together (depression, catastrophizing, fear-avoidance, anxiety, somatization), each of these themes were accounted for in at least one of the aforementioned reviews (Linton, 2000; Hasenbring et al., 2001; Pincus et al., 2002). Furthermore, their prevalence throughout CLBP literature is significant. Depression, anxiety, fear-avoidance behavior and catastrophizing were the main psychological factors highlighted in Dun et al. (2004) review of the epidemiology and natural history of CLBP and Manchikanti et al. (2009) comprehensive review of the epidemiology scope and impact of spinal pain (somatization was also highlighted in Manchikanti review). Therefore, incorporating all five themes into one study is a logical idea. The following five sections are dedicated to briefly reviewing each of these five psychological research themes. Although this literature is strictly based prospective and cross sectional research, it usefully outlines each factor and their role in the CLBP experience. Most importantly, this section will distinguish understudied areas of research in the field of CLBP literature and how phenomenological inquiry can appropriately address such concerns.

## Depression

Depression is characterized by self-directed negative thoughts containing themes of loss, failure, and devaluation (Barton & Morley, 1999). Depression is a highly prevalent symptom among CLBP patients as the degree of pain is associated with severity of depression (Von Korff & Simon, 1996; Bener et al., 2006), while research has also linked depression to the transition from acute to chronic LBP (Hasenbring et al., 2001). Finally, depression is clearly associated with less successful

treatment outcomes, as misdiagnosing or mistreatment has been found to influence levels of depression (Burns, Johsnon, & Mahoney, 1998).

The problem with research on depression and CLBP lies within the variability of assessment. Firstly, certain pain clinics are more commonly associated with depression than others and the incidence of depression may vary across treatment settings (Williams, 1998). Secondly, there is an overlapping symptomatology of chronic pain and depression, which is referred to as criterion contamination (Williams, 1998). The diagnostic criteria for depression includes several somatic symptoms that can also be attributed to chronic pain (e.g. sleep disturbance, motor retardation, loss of energy, and change in appetite and weight) and this can make diagnosing depression in populations of chronic pain very tricky (Gatchel & Dersh, 2002). Criterion contamination (Williams, 1998) may become particularly problematic when assessing depression with psychological instruments that have been standardized on psychiatric populations who do not experience significant physical illness and disability, such as the Beck's Depression Inventory (BDI). (Wesley, Gatchel, Garofalo, & Polatin, 1999) This is evident as CLBP patients will often resemble depressed patient scores rather than normal control scores for the somatic items, while pain ratings for cognitive and affective items will resemble normal control scores (Williams & Richardson, 1993). This, creates an overestimation of depression in CLBP samples when using the Beck's Depression Inventory (Beck, Steer, & Brown, 1996) and/or other depression questionnaires (e.g. Zung self rating depression scale) (Williams et al. 1993; Tae-Suk et al., 2006).

The BDI has been documented as a useful method for generating important information about the severity of interference posed by pain on the functioning of an individual. However, Wesley et al. (1999) suggests there also needs to be an independent evaluation of subjective experiences of depression and somatic disturbances. Therefore, phenomenological inquiry is well suited to identify potential depressive experiences in CLBP patients, while providing them with an opportunity to connect these experiences to their chronic illness in a way that is meaningful to them.

## Catastrophizing

Pain catastrophizing is defined as a tendency to ruminate, magnify, or feel helpless about pain, is characterized by an exaggerated negative interpretation of pain, and the perception that any painful encounter will prove insurmountable (Spanos, Radtke-Brodorik, Freguson, & Jones, 1979; Sullivan et al., 2001). Catastrophizing is associated with pain disability and may be related to intensified pain in CLBP patients (Peters, Vlaeyen, & Weber, 2005; Buer & Linton, 2002). Research indicates that catastrophizing is related to exaggerated responses to ALBP (France, al'Absi, Ring, & McIntyre, 2002; Sullivan et al., 1997) and poor adjustment to CLBP (Sullivan et al., 2001). This may be because pain disengagement as opposed to pain acceptance is highly characteristic of pain catastrophizers with CLBP (Quartana & Burns, 2007; Van Damme, Crombez, & Eccleston, 2004). Quartana et al. (2007) recently provided scientific evidence demonstrating that CLBP among high pain catastrophizers may be affected by exaggerated symptom-specific muscle

tension levels, however, the potential mechanisms by which catastrophizing serves to maintain and/or exacerbate CLBP are poorly understood (Quartana et al., 2007).

Catastrophizing is a highly subjective experience, as pain catastrophizers reflexively engage in a pattern of faulty processing in which they interpret the meaning of painful experiences so that negative outcomes are anticipated (Michael & Burns, 2004). Therefore, phenomenological investigation will help to assess and understand the catastrophizing experiences of CLBP patients as they relate to both the acute and chronic phases of LBP.

## Fear-Avoidance

Fear avoidance is behavior aimed at postponing or preventing an aversive situation from occurring (Leeuw et al., 2007). With respect to CLBP it is the possibility to avoid activities that are assumed to increase pain or (re)injury (Leeuw et al., 2007). The Fear Avoidance Model (FAM) (Lethem, Slade, Troup, & Bentley, 1983; Philips, 1987; Waddell, Newton, Henderson, Somerville, & Main, 1993; Vlaeyen, Kole Snijders, Boeren, & van Eek, 1995; Vlaeyen & Linton 2000) has gained significant empirical support to suggest that fear of pain, leading to avoidance behavior and hyperviligance (selective attention towards possible sources of threat) may contribute to the maintenance of CLBP (Leeuw et al., 2007). The model suggests that if acute pain is interpreted as threatening, possibly through the cognitive process of catastrophizing, pain-related fear may evolve. This leads to avoidance behavior and hypervigilance to bodily sensations and pain, which maintains a chronic pattern of disability, disuse, and depression. Both depression and disuse are associated with

decreasing pain tolerance, which promotes the painful experience and fuels the cycle of increasing fear and avoidance behavior.

CLBP patients with heightened levels of pain-related fear report increased disability (Peters, Vlaeyen, & Weber, 2005; Boersma & Linton, 2005; Denison, Asenlof, & Lind berg, 2004), however, the mechanisms underlying this connection are uncertain (Leeuw et al., 2007). While it is clear that avoidance behavior can have an impact on daily life tasks (Vlaeyen et al., 2000), hypervigilance can also contribute to disability as selective attention to pain related stimuli and the associated difficulty with disengaging from those stimuli might occur at the cost of vigilance to usual every day tasks (Leeuw et al., 2007). However, whether the association between pain-related fear and disability are mediated by avoidance/escape behaviors and/or hypervigilance has not been examined (Leeuw et al, 2007). Phenomenology provides an excellent opportunity to address this concern, as interpersonal discussion will help unveil CLBP patients' psychological interpretations of this connection (Creswell, 2007).

In addition to the onset of disability, frequent avoidance behavior may contribute to a deterioration of physical fitness. The term "disuse syndrome" refers to the physiological effects of a reduced level of physical activity in daily life, as frequent avoidance of activity may also result in a deterioration of a person's muscular system and physical fitness (Verbunt et al., 2003). Thus far, lower or equal daily life activities were found when comparing CLBP patients with healthy controls, although the number of studies is rather small (Nielens & Plaghki, 2001; Spenkelink, Hutten, Hermens, & Greitemann, 2002; Verbunt et al., 2001). Currently, neither

lower physical activity levels nor the physical consequences of long-term avoidance behavior in CLBP patients have been unambiguously confirmed. It may be that CLBP patients avoid activities that they perceive will increase pain, but in general maintain their physical activity levels when compared to healthy people (who may be inactive themselves) (Verbunt et al., 2003). This might explain their serious functional limitations despite unaffected activity levels. Leeuw et al. (2007) urges more research on the physical consequences of CLBP within affected patients as opposed to between groups to elucidate the contribution of disuse in CLBP. The idiographic investigation of IPA (Smith et al., 2003) will provide the researcher with an opportunity to address this concern.

**Anxiety**

Persons with CLBP often demonstrate clinically significant levels of anxiety about pain (Vowles, Zvolensky, Gross, & Sperry, 2004), and incidence of generalized anxiety disorder is highly common (Manchikanti, Vidyasagar, Beyer, Damron, & Barnhill 2002a; Manchikanti, Fellows, & Pampati, 2002b). Furthermore, pain-related anxiety has been highlighted as one of the most disabling aspects of the chronic pain experience (Turk and Okifuji, 2002b; Vlaeyen et al., 2000).

Anxiety and fear-avoidance seem to be connected as heightened levels of anxiety about pain are believed to contribute to avoidance of activities. Specifically, heightened levels of anxiety about pain are believed to contribute to avoidance of activities that are perceived to promote pain, which in turn often lead to physical deconditioning, secondary behavioral problems (e.g., weight gain), and reduced social contact (Hadjistavropoulos & LaChapelle, 2000). However, this conflicts with the

FAM, which claims that fear of pain, not pain anxiety leads to avoidance behavior (Lethem et al., 1983; Philips, 1987; Waddell et al., 1993; Vlaeyen et al., 1995; Vlaeyen et al., 2000).

Although fear and anxiety are two separate constructs, they are used interchangeably in the clinical setting (Leeuw et al., 2007). Fear is the emotional reaction to a specific, identifiable and immediate threat, such as a dangerous animal or an injury (Rachman, 1998). Anxiety is a future oriented affective state characterized by cognitive, somatic, emotional, and behavioral components, which combine to create feelings of fear, apprehension, or worry (Seligman, Walker & Rosenhan, 2001). Fear is associated with defensive behaviors (e.g. escape) while anxiety is associated with preventative behaviors (avoidance) (Leeuw et al., 2007). The FAM uses fear and anxiety of pain interchangeably; however, Asmundson et al. (2004) tried to differentiate between the two in an updated version of the FAM. In Asmundson's et al. (2004) version, there is no longer a direct link between fear of pain and avoidance behavior, because by definition one cannot avoid a threat that is already present. Instead, they added an anxiety pathway in the anticipation of pain to the fear pathway in the presence of pain. The anxiety pathway then leads to avoidance behavior, which in turn leads to disuse, disability, and depression. There is no evidence to suggest that this updated model adds value to the original one, while there is currently a debate about clinical distinctiveness of fear and anxiety (Leeuw et al., 2007). With the appropriate questioning, semi-structured interviews should provide CLBP patients with sufficient time to formulate accurate descriptions of whether their

avoidance or escape behavior was previously and/or currently based on fear of pain or pain anxiety (Kvale, 2007).

Banks and Kerns (1996) proposed a diathesis-stress model for the development of psychopathology in chronic pain patients. In this framework, the diatheses are characterized as pre-existing, semi-dormant characteristics of the individual before the onset of chronic pain, which are then activated by the stress of the chronic condition. Stress refers to the nature of the chronic pain experience. Although the Banks et al. (1996) model was originally applied to depression it may also be applicable to the relationship between CLBP and anxiety disorders. Polatin, Kinney, Gatchel, Lillo, and Mayer (2000) found that the stress of the CLBP experience exacerbated a genetic disposition to anxiety disorders, suggesting that anxiety in some instances can precipitate CLBP. Further research is needed to understand the stressful nature of the chronic pain experience, and to clarify the factors that mediate the relationship between diathesis/stress and the development of anxiety, depression, and other forms of diagnosable psychopathology (Dersh, Polatin, & Gatchel, 2002). Phenomenology is advantageous for such research goals given its dedication to understanding the lived experiences of a phenomenon (Patton, 2002). Furthermore, the semi-structured interview provides the researcher an opportunity to explore and clarify the mediating factors between diathesis, chronic pain, and physiological distress throughout the CLBP experience.

**Somatization**

There is a general non-specificity in terms of the relationship between personality/psychological problems and pain and significant psychopathology

typically develops (or recurs) only after months of experiencing disabling pain (Turk, 1996). However, there seems to be a subset of chronic pain patients who demonstrate a consistent tendency to experience and communicate emotional distress as somatic symptoms (Fishbain, 1998). This syndrome, which may or may not approach the severity of a somatoform disorder,[8] has been called somatization. Somatization involves the focusing of attention on internal stimuli and the denial of psychological or interpersonal difficulties, resulting in an increased tendency to report somatic symptoms, many of which cannot be medically explained (e.g. pain, gastrointestinal, sexual and pseudoneurological symptoms) (Simon, Von Korff, Piccinelli, Fullerton, & Ormel, 1999). Somatization is one of the five somatoform disorders recognized by the Diagnostic and Statistical Manual of Mental Disorders.[9]

CLBP has been long associated with emotional distress, but it has also been observed that individuals with intractable CLBP frequently report multiple somatic complaints beyond pain itself (Bacon et al, 1996). Somatizing CLBP patients often express psychological and social distress as persistent, medically unexplained physical symptoms (Bacon et al., 1996). Major depression has been found to be associated with severity of somatization, while greater functional impairment, but not pain intensity, has also been related to a high level of somatic complaints in CLBP patients (Bener et al., 2006; Bacon et al., 1996). Somatization is associated with an increased risk for developing CLBP, greater health utilization in ALBP patients and

[8] Somatoform disorders are a group of psychological disorders in which a patient experiences physical symptoms that would suggest a general medical condition, despite the absence of an underlying medical condition, substance use, or other mental disorders (Bener et al., 2006).

[9] The Diagnostic and Statistical Manual of Mental Disorders (DSM) is an American handbook for mental health care professionals that lists different categories of mental disorders and the criteria for diagnosing them, according to the publishing organization the American Psychiatric Association. The most updated version is the DSM-IV.

poorer treatment outcomes in CLBP patients (Pincus, Burton, Vogel, & Field, Simon et al., 1999)

Although somatization is prevalent in many CLBP patients, there are no universal symptoms (Bener at al., 2006; Bacon et al., 1996). In fact, somatization disorder is not only complex, but is also a complicated and controversial psychiatric diagnosis, which can vary from person to person (Manchikanti et al., 2002a; Manchikanti et al., 2002c). Therefore, a better understanding of the onset, risk, and nature of somatization symptoms in homogeneous pain samples (e.g. just CLBP) is needed (Manchikanti et al., 2002a). Specifically examining patients with CLBP combined with the psychological nature of IPA provides a formidable context to address such concerns.

**Qualitative Literature**

All phenomenological research on the lived experiences of CLBP was included in this review. Additional exploratory qualitative studies contributing information on the CLBP experience were included as well. This included mixed methods studies (in this case, studies combining both quantitative and qualitative methods) (Johnson & Onwoegbuzie, 2004), narrative research (Kleinman, 1988); studies using the framework approach or a topic guide (Ritchie & Spencer, 1994) and focus group research (Morgan, 1997). These forms of qualitative research are similar to phenomenology in that they are exploratory in nature; use interviews as the primary source of data collection (not always true for mixed methods) and typically gather rich and in-depth data. Such an encompassing qualitative literature review is advantageous for several reasons. Firstly, qualitative research elucidates the

subjective experience of pain and has been recognized as particularly useful for providing important information about the psychosocial context of chronic pain patients' lives (Mathieson & Barrie, 1998). Therefore, studies which have theoretical similarities with phenomenology can enhance our understanding of the CLBP experience. Secondly, reviewing different forms of exploratory research provides a unique opportunity to examine how past research has addressed any of the five aforementioned psychological research themes. Thirdly, reviewing exploratory qualitative pain research affords an opportunity to identify other psychosocial issues of salience in the CLBP experience. Potential recurring themes can provide the researcher with valuable topics of interest to explore and expand upon, in conjunction with the primary research goals.

Inclusion criteria for the review included phenomenological studies, mixed methods studies (Johnson et al., 2004), narrative research (Kleinman, 1988), studies using the framework approach or a topic guide (Ritchie et al., 1994), and focus group research (Morgan, 1997) related to the CLBP experience. Studies must have used interviews as the primary data collection method and must have focused on the experiences of CLBP from the perspective of the patients themselves. Exclusion criteria included any studies not written in English and studies focusing on chronic pain but not CLBP specifically. PubMed and Academic Search Premier were the databases or search engines used to locate and select articles for this review. Key terms for different searches included; phenomenology and chronic low back pain, phenomenology and low back pain, phenomenology and chronic pain; narratives and chronic low back pain; low back pain narratives; qualitative research and chronic low

back pain; qualitative research and low back pain; low back pain and the framework approach, low back pain and mixed methods research and low back pain and focus groups. At first, twenty articles were selected for review; however, this was narrowed down to seventeen as three articles were written in a foreign language. The seventeen articles included eight phenomenological studies; four mixed method studies; three studies based strictly on narrative accounts; one study using a 'framework approach' endorsing Ritchie et al. (1994) framework analysis; and one focus group study. However, the framework approach was used in some of the mixed methods studies as well.

Phenomenological Research

Using Giorgi's (1985) phenomenological method of analysis,[10] Bowman (1991) examined the meaning of CLBP on fifteen (nine women; six men), unemployed, CLBP patients. Participants were recruited from a pain management clinic in the US and were asked to describe what it was like to live with CLBP.

Details of the study are extremely limited but the researcher felt the meaning of CLBP could be perceived through the altered lifestyle patients adopted to accommodate their pain and through a decreased quality of life. The former was evidenced by a major decrease in activities of daily living and loss of employment. The latter was evidenced by major feelings of helplessness and despair, due to a continuous cycle of unremitting pain, followed by medical counseling and surgery, without pain relief.

[10] Giorgi's (1985) phenomenological method is a form of existential phenomenology that is used in psychological research and focuses on capturing the essential meaning of an experience.

Bowman (1994a) described the aspect of experiencing CLBP, based on data from Bowman (1991). Analysis showed that each participant discussed experiencing CLBP through a series of events. The pain experience would commence with the occurrence of injury. Then participants would seek medical help to locate the cause of pain and alleviate it through medications and surgical treatments. This most often resulted in a lack of relief that frequently caused the individuals to seek help again. During this process the individuals had to deal emotionally and psychologically with uncertainty and at some point, each individual realized the inevitable nature of their pain and decided that he/she needed to learn to live with it. However, participants had difficulty coping with this acceptance as they were never able to find a cure. Meanwhile, in some cases the inevitability of long term pain led to depressive symptoms, while others felt that long term pain had totally "messed up" their life.

Bowman (1994b) examined CLBP patients reactions to pain, and two main themes were discussed; altered interactions and varied psychological reactions. Altered interactions referred to how individuals would not react "normally" when experiencing pain. The reactions were often negative, as patients were short tempered. All participants had a desire to be independent and shared an increased subjective awareness with others in pain. Most participants reported being isolated by their pain, either by conscious choice or through a situation imposed by others.

Some of the varied psychological reactions to pain described by the patients include: a determination to control their pain, feeling embarrassed to admit their pain and a depressive mood from stigmatization. The latter explained that patients often felt self conflicted and depressed as a result of an inability to cope with those who

failed to understand their pain and subsequently stigmatized them as having an "attitude problem." Bowman's work introduced CLBP patients frustrating interactions with the medical model and highlighted some important resulting themes (despair and stigmatization) that will resurface throughout this review.

Walker, Holloway, and Sofaer-Bennett (1999) explored CLBP patients' views of their lives to provide an 'insider' perspective on CLBP at the point when patients seek help from pain treatment centers. Narrative interviews were conducted on a sample of twenty newly referred patients (12 M; 8 F) from a pain clinic in southern England. Using Giorgi's (1985) phenomenological method of analysis, the researchers developed the theme 'in the system' to describe how participants became entrapped within the medical, social security and legal systems, as the very systems designed to help and protect those who are ill, injured and disabled effectively rendered patients powerless, helpless and angry. This supports the view that the medical system encourages passivity, chronicity and powerlessness (Waddell, 1992) through encouraging individuals to focus on a non-existent cure (Seers & Friedli, 1996) and by encouraging bed rest as an effective treatment for ALBP (Cherkin, Deyo, Wheeler & Ciol 1996). Throughout their experiences 'in the system' participants felt largely misunderstood and stigmatized, as there was no obvious sign or pathology to validate their suffering, making it difficult to come to terms with their future. Frustration with 'the system' was expressed by all of those interviewed, while many participants tried to hide feelings of anger. Anger appears to be a salient feature of the chronic pain experience that is often suppressed (Fernandez & Turk, 1995). Walker at al. (1999) believe this is because there is rarely anyone at whom the anger

can be directed, as it may be perceived as unreasonable to express anger at those trying to help (medical physicians, benefits agencies, lawyers etc). This may explain why it was not accounted for in the previously documented systematic reviews on the psychological connection to CLBP (Linton, 2000; Hasenbring et al., 2001; Pincus et al. 2002).

In a similar study Walker, Sofaer-Bennett, Holloway (2006) adopted an interpretive phenomenological approach (Smith et al., 1997) to explore the lived experiences of sixteen CLBP patients' prior to their seeking help from a pain clinic in the UK. A continuing idea throughout the data analysis was the theme of loss; the life events or changes that resulted in the participants being or feeling deprived of something they valued. Participants reported loss of physical and mental abilities, employment-related losses, relationship losses; including friendships and marriages, and loss of identity. The latter referred to how those of working age drew a distinction between their public and private self. Many participants completely lost their self-esteem, which was exacerbated by the responses or anticipated responses of others. Loss of hope and total despair was a major underlying theme that explained how many patients were afraid of what the future would bring. Many working-aged participants lived in constant fear of further injury, which is consistent with current literature on fear-avoidance behavior (Goubert et al, 2004a). Meanwhile, only three participants accepted their pain, as the rest conceptualized their referrals to the pain clinics as a last resort to end their suffering.

Results from Walker et al. (2006) explain how patients suffered different material and psychological losses attributed directly to their CLBP. Participants'

stories were filled with thoughts that may be considered catastrophizing as previously defined in this paper. Pincus and Morley (2001) indicate that negative cognitive bias and feelings of worthlessness may be a result of a particular type of enmeshment of three schemas: pain, illness and the self. They suggest that pre-existing vulnerability in the self schema may, in combination with the pain schema, lead to increased dependence and distress. However, stories told by the participants in Walker et al. (2006) suggest that the negative material and social consequences of CLBP may be sufficient to generate feelings of worthlessness and hopelessness even where no latent personal vulnerability in "the self" existed prior to the onset of pain. This supports Gatchel et al. (2002) idea that catastrophizing may be a realistic appraisal of tangible losses experienced as a direct consequence of having CLBP. Therefore, it may be beneficial to focus on situational explanations for cognitive biasing rather than just self-referential explanations.

Holloway, Sofaer-Bennett, and Walker (2007) again used IPA to examine the experiences that shape the beliefs, attitudes, and needs of CLBP patients attending pain clinics. Their study was focused on conceptualizing the experiences of eighteen (12 M; 6 F) middle-aged CLBP patients attending pain clinics in Southern England. In depth, narrative interviews permitted participants 'to tell their story.' Much like their previous work (Walker at al. 1998; Walker et al. 2006), the results of this study focused on one main theme; stigmatization.[11] This concept arose specifically from the data as participants did not use this specific word. All participants reported a 'moral stigma' from health care professionals who doubted the physical reality and the

[11] Stigma is defined as a trait that is discrediting to the observer or any trait the owner attempts to conceal because it is perceived to be discreditable (Goffman, 1963).

legitimacy of persistent back pain due to an inability to properly identify and diagnose physical causes of pain. This moral stigma was also related to feelings of stigmatization within their social life, as a lack of a diagnostic label and the invisibility of pain made communication with family and friends difficult. Patients also identified a 'work stigma', as patients who were without employment (all but one), struggled to retain work and were not supported by unsympathetic employers. Finally the participants felt stigmatized in their everyday lives, particularly when they manifested signs of illness (e.g. using crutches, walking with a limp).

The previous three studies illustrate how Walker, Sofaer-Bennett, and Holloway have efficiently and appropriately used phenomenology to determine the essence of the CLBP experience of those suffering in the UK. Essentially, this is an experience "trapped" within different systems (Walker et al., 1998), characterized by feelings of loss (Walker et al, 2006) and stigmitisation (Holloway et al. 2007). However, these studies showed various conceptual similarities to two of the five research themes identified in the introduction. Walker et al. (2006) in particular managed to provide meaningful insight on hopelessness and fear, as well as personal vulnerability and catastrophizing.

Osborn and Smith (2006) also adopted an interpretive phenomenological approach (Smith et al., 1996) to study CLBP. However, the researchers endorsed a more intrapersonal approach, as they focused on the personal experience of CLBP in relation to each participant's body and sense of self. Semi-structured interviews were used on six CLBP sufferers in the UK to explore the different ways pain had affected or influenced their feelings, attitudes, and beliefs about themselves. A major theme

was living with a body separate from the self. This is a dualistic idea which explains that any dysfunctional or painful part of the body (painful self) was placed outside of the self by the participants and considered "not me". Meanwhile, those parts of the body which functioned normally (preferred self) were taken for granted and given little conscious thought or attention. Osborn et al. (2006) managed to augment research by Williams (2000) in demonstrating how participants' self-concept and their painful bodies were defined more by alienation and exclusion than acceptance or integration. Furthermore Osborn et al. (2006) encourage more research on the relevance of this aspect of the pain experience and the degree to which the new and everyday prominence of a body which could no longer be taken for granted can influence the sufferer's experience. Osborn et al. (2006) must be commended for examining embodied experiences, as pain research has been criticized for ignoring the body and thus producing a 'disembodied' account of chronic pain experience (Kelly & Field, 1996)

Another qualitative study of back pain conducted by Benjaminsson, Biguet, Arvidsson, & Nilsson-Wikmar (2007) aimed to explore and describe the different ways in which patients with recurrent LBP perceive and respond to the reoccurrence of pain. The researchers conducted semi-structured interviews on seventeen (10 M; 7 F) Swedish CLBP patients who had suffered a relapse of intense LBP during the last year after a pain free period of time. Benjaminsson et al. (2007) created four qualitatively different categories of reasoning and responses to the recurrence of pain based on interview data.

Participants in category one, entitled; [12]*relapse: an unsolved mystery – a source of uncertainty and self accusation*, relied on fear-avoidance behavior to cope with their pain. These patients maintained an external locus of control through relying on others for help (e.g. a constant search for medical solutions) which led to passive coping strategies such as catastrophizing and feelings of guilt. These findings support the idea that fear-avoidance behavior may be linked to the transition from acute to chronic LBP (Leeuw et al., 2007). Participants in category two, entitled; *relapse: an obvious part of life that has to be ignored*, were not interested in understanding why pain recurs and ignored their pain. Ignoring pain was mentioned as a coping strategy for relapses; however, this lead to depression and hopelessness in some cases. Participants in category three, entitled; *relapse: a reminder to keep within limits both physically and psychologically* were aware of, and could understand the cause of their relapse, but were not able to prevent further relapse. They continued to practice hard sports and work many hours which sometimes lead to mental stress and physical overload. They seem to have difficulty dealing with a stressful lifestyle. Participants in category four, entitled; *relapse: an indication to change behavior and prevent further relapse* were proactive in the way they coped with pain, as they showed increased self-efficacy for different self-management skills. They did not ignore their recurrent pain, but rather used it to help them realize, accept, and cope with their problems, and to make changes to prevent further relapse.

The results from Benjaminsson et al. (2007) suggest that patient's experiencing a relapse of LBP can respond in different ways and show different degrees of readiness to adopt self management approaches to prevent further relapses.

[12] All themes/categories presented are italicized

Therefore, a patient's level of readiness to change may dictate the nature of their CLBP experience. For example, those participants experiencing relapses in a state of uncertainty (stage 1) coped with their pain through catastrophizing and fear-avoidance behavior, whereas, those participants who accepted but ignored their relapses (stage 2) felt a sense of hopelessness and depression. However, despite the variation of behavior across all four categories, both overestimation of one's physical capacity and a stressful lifestyle were commonly perceived as triggers or contributing factors for relapse of LBP in all four categories. Although Benjaminsson et al. (2007) adopted a novel approach to phenomenology; the stages of change construct has been applied to CLBP in the past through the use of the Pain Stages of Change Questionnaire (POSCQ) (Kerns & Habib, 2004; Pfingsten, Schops, Wille, Terp, & Hildebrandt, 1997).

Mixed Methods Research

Different researchers have adopted a mixed methods approach (Johnson et al., 2004) to study specific aspects of CLBP, while still adhering to the exploratory nature of qualitative research. Generally, these studies combined subjective interviews with some form of objective assessment (e.g. pain questionnaire). Both Glenton (2003) and Waters, Keefe, and Strauman (2004) utilized the mixed methods approach to explore specific aspects of the chronic pain experience in relation to different theoretical concepts.

Glenton (2003) managed to provide unique insight on the potential origins of stigmatization and deligitimation on CLBP patients from Norway, as they relate to the sick role. Through a mixed method design, data was collected via discussion list

contributions from a Norwegian Back Pain Association website (www.ryggforeningen.no) and through in-depth interviews on nineteen patients of several different Norwegian health clinics. The "sick role" is a concept which explains that the degree in which the illness experience is transformed into sickness dictates the degree to which a person's experience of an illness will be accepted by his/her surroundings (Frankenberg, 1980). In other words, the sick role is a position that sick/injured/ill people can achieve if their illness becomes socially meaningful (Frankenberg, 1980). To achieve the sick role is to achieve recognition of ones suffering and is also a social license to be exempt from particular duties for a given period of time. Individuals who experience bodily suffering but fail to gain acceptance for this suffering find themselves with illness, but without sickness. This often leads experiences of deligitimation and stigmitzation. Therefore, given the difficulty in formally diagnosing CLBP, it is clear that expectations of the sick role are inappropriate for this particular illness (Glenton, 2003). However, results from this study suggest that the sick role concept still appears to reflect the expectations of health care professionals, the public, and most importantly, the patient him/her self. According to Goffman (1963) stigma can be associated with character blemishes which include; weak will, dishonesty, addiction or mental illness. CLBP sufferers in this study feared accusations of all these traits and thus were constantly seeking a medical diagnosis to confirm or validate their illness.

Although others may meet the identification of a disease with dismay because of serious implication on health or social stigma (e.g. lung cancer), CLBP sufferers in this study and others (Rhodes, McPhillips-Tangum, Markham, & Klenk, 1999)

encouraged a positive diagnostic test as "proof" of their suffering. Many patients choose to hide their psychological problems and refused to challenge their doctor's view of the connection between mental health and CLBP, fearing that openness would lead to a delegitimation of their experience of physical pain. CLBP patients described the feeling that their experiences of suffering were being questioned and reported feeling of deligitimation. However, rather than challenge these concepts about sickness and suffering tied to the delegitimation of their experiences, the CLBP sufferers tried to fit into the medical system by constantly striving to live up to the expectations of the sick role. Therefore, it seems as if the passive and submissive nature of CLBP patients compels them to conform to unreal expectations of the social and medical community, which ironically leads to the feelings of stigmatization that they are trying to avoid.

Waters et al. (2004) adopted a mixed method approach to examine the notion of self-discrepancy and its relation to pain, depression, and psychological distress in a sample of CLBP patients. Self-discrepancy theory maintains that discrepancies between who people believe they are and who people believe they would like to be or they ought to be, significantly influences their emotional state (Higgins, 1987). The researchers used semi-structured questionnaires to assess self-discrepancies, along with standardized measures to assess pain intensity, depression and psychological distress in ninety-three CLBP pain clinic patients in North Carolina. Results indicated that patients with large discrepancies between actual-self (how a person currently views him/her self) and ought-other-self (the attributes that a person believes he/she has an obligation to possess) reported more severe pain and higher levels of

psychological distress. Meanwhile, patients with large discrepancies between actual-self and ideal-self (how a person would ideally like to be) reported higher levels of depression and psychological distress. These findings suggest that self-discrepancies are related in meaningful ways to measures of pain, depression, and psychological distress in CLBP patients. Self-discrepancy theory also takes into account ought-self (who a person feels they ought to be) and ideal-other self (a person's perception of how significant others wish they could be). However, these constructs were not found to be related to the variables of interest.

In the clinical setting, back-related functional limitations are largely assessed using indices or lists of activities, each scored on a yes/ no basis and the scores then summed. However, these objective accounts rarely encapsulate the subjective experience of chronic pain. De Souza and Frank (2000; 2007) used a mixed methods approach to test the applicability or relevance of functional assessment protocols for assessing functional and psychological problems in CLBP patients. In De Souza's et al. (2000) exploratory study on how eleven CLBP patients perceive and understand their pain, interview data was compared with the type and range of pain descriptors used for the McGill Pain Questionnaire (MPQ) (Melzack, 1983). Nearly all subjects provided descriptors of the quality of their pain; however, only thirteen of twenty-nine different pain descriptors used by the participants corresponded with those of the MPQ (Melzack, 1983). The use of simile was common to emphasize both what the pain was and what it was not, while some had a loss of words in trying to describe their pain. Furthermore, subjects had great difficulty quantifying their pain intensity. Several explained how the pain fluctuated, thus, quantifying pain at one point in time

was problematic. Only one subject offered a numerical description of pain. Subjects provided graphic and in-depth descriptions of their pain experience, but these bore little resemblance to commonly used assessment tools.

De Souza et al. (2007) explored the physical consequences of living with day-to-day CLBP to document the 'insider' accounts of how pain impacted daily activities. Eleven patients were recruited from a rheumatology outpatient clinic and their descriptions of the impact and consequences of CLBP were compared with formal assessment measures of LBP disability (Roland and Morris Questionnaire) (Roland & Morris, 1983) and depression (Modified Zung Score) (Main, Wood, Hollis, Spanswick, & Waddell, 1992). In relating their experiences of living with spinal pain, subjects expressed regret at the loss of their physical capabilities and distress at the functional consequences of those losses. Participants were particularly concerned about lack of sleep/rest, decreased mobility, decreased personal independence leading to increased helplessness, and decreased leisure time. Subjects provided rich accounts of their physical state and revealed problems that were not evident by the standardized assessment tools participants completed in the study. This is alarming considering that mobility disability is addressed in most commonly used back pain assessments and the Roland and Morris Questionnaire (Roland et al., 1983) has the widest range of mobility items. These articles (De Souza et al., 2000; 2007) link qualitative research to clinical data in comparing 'insider accounts' of the chronic pain experience with formal assessment measures of pain on samples of eleven (5 M; 6F), newly referred CLBP patients of rheumatology outpatient clinics in the UK. Both studies managed to illustrate that the ways CLBP patients conceptualize their chronic

pain experience bared little resemblance to commonly used assessment tools. Although only some assessment tools are addressed, the researchers do present a challenge to clinical medicine to refocus assessment and treatment to 'client-centered' rather than 'pain-centered' approaches.

In the case of De Souza et al. (2000; 2007) quantitative and qualitative methods of data collection contributed unique outcomes, as results of the latter helped to inform results of the former. However, researchers also used the mixed-methods approach to examine the role of specific theories within the context of CLBP. For example Glenton (2003) found that the sick role is a prominent ideology in the lives of CLBP patients. Furthermore, stigmatization continues to persist as an emerging theme in this review. However, the effects of stigmatization on the psychological research themes (from the introduction) and vice versa, has not yet been made clear. Waters et al. (2004) applied self discrepancy theory (Higgins, 1987) to CLBP and psychological distress and found that disparities in actual and ideal self can increase feelings of depression. However, the role of CLBP in this connection is not entirely clear.

Narrative Research

Ong, Hooper, Dunn, and Croft (2004) and Lillrank (2003) used narrative research to examine the patient-doctor interaction during the time when CLBP patients seek medical counsel. Ong et al. (2004) examined the experiences of living with pain and accessing professional help in a small group of CLBP patients in the UK. Their prime focus was to analyze how CLBP narratives can be interpreted as a way in which sufferers communicate and legitimize pain and negotiate meaning

within clinical encounters. Patients from this study attempted to communicate and legitimize their pain as authentic by calling on shared experiences and knowledge or by retelling drama of pain, while they presented their own interpretations as uncontestable. This is not surprising as CLBP patients feel largely misunderstood and stigmatized when there is no obvious sign or pathology to validate their suffering (Walker et al., 1999; Holloway et al., 2007; Glenton, 2003). Clearly CLBP is not a justified illness in the medical community and patients must work to establish the authenticity of their suffering. Some participants negatively cope with this by suppressing their frustration and passively adhering to medical protocol for fear of stigmatization (Walker et al., 1999; Glenton 2003). However, it is this battle for legitimization of pain that makes for unique experiences. In the case of Ong et al. (2004) in order for patient's to legitimize their pain, they recognized that the scientific approach demanded precision and measurement. However, pain location, patterns and severity were often variable, thus providing reliable and measurable information to their physician was difficult. Therefore, patients had to either adopt a bio-medical terminology or juxtaposed law knowledge with scientific expertise. It seems the latter increased patient control in the negotiations about diagnosis and treatment. The presentation of the self to health care professionals involves a complex process of expressing feeling and experiences with mapping clinical terminology onto lay understanding. It is clear the results discussed from this study are highly connected with the inner desire of CLBP patients to legitimize their pain.

A study by Lillrank (2003) examined the process of getting CLBP diagnosed through analyzing the narratives of thirty middle-aged Finnish women. An

overwhelming theme was the lived certainty of pain versus the medical uncertainty of pain. Essentially the CLBP was real to the participants, however doctors continually adopted the inaccurate mind-body dichotomies that nullified each patients subjective experiences and this was socially stigmatizing. Furthermore, the opportunity to finally be diagnosed was a great relief, but to be taken seriously as a person was an even greater relief. It is clear from both Linrank (2003) and Ong et al. (2004) that CLBP patients not only seek medical council to resolve their pain but also engage in some kind of negotiation with their physician to prove that they are legitimately sick. The previous two studies convey the idea that it is the role of the patient to establish the authenticity of their suffering, as CLBP itself is not enough to legitimize their suffering in the eyes of the clinician (Walker et al., 1999; Holloway et al., 2007; Glenton, 2003; Ong et al., 2004; Lillrank, 2003)

Other narrative research has focused on the emotional response to pain, as Corbett, Foster, & Ong (2007) examined the struggle between hope and despair through consideration of six people's narratives on their "non specific" CLBP experience. The six participants were selected from a larger study in the UK, which explored the personal experiences of living with non-specific CLBP. A number of influences that mediated fluctuations between hope and despair were found. Doubt through medical uncertainty lead to feelings of hopelessness for finding a cure. However, doubt also redirected the individual towards hope, as this left open the possibility that there was a potential cure for them. The connection between the physical pain and psychological distress impacted the dynamic between hope and despair. More persistent pain increased psychological despair and feelings of

hopelessness, however controlling the pain improved psychological well-being and increased feelings of hope. Worry and fear about the future also mediated feelings of hope and despair as some participants felt they would never find a cure, while others maintained that someday things would change for the better. It is clear that the uncertainty of non specific CLBP has many resulting influences that mediate feelings of hope and despair in CLBP patients. Furthermore, hope and despair shape people's perceptions of their illness and can be used to better understand the psychosocial impact of pain on the daily lives of those with recurrent LBP (CLBP). The narrative research presented here has demonstrated that patient responsibility and involvement is an essential component of pain management (Lillrank, 2003; Ong et al., 2004); however, there has been little exploration of patients' expectations and opinions about CLBP and its management (May, 2007).

The Framework Approach and Focus Group Research

May (2007) conducted a qualitative study in the UK on physiotherapy patients' perspectives and attitudes about CLBP and its management. Semi-structured interviews for thirty-four participants (20 M; 15 F) were analyzed using Ritchie et al. (1994) framework analysis. Not surprisingly, many patients' expressed dissatisfaction about ineffective medical management and feelings of deligitimization based on inappropriate advice and a lack of empathy (Osborn et al. 2006; Holloway et al., 2007). However, all patients were interested in self-help and investing in self-management of their CLBP. For the most part, self-management strategies lead to feelings of independence which increased patients' perceived control over their illness. This supports Waddell's (2004) suggestion that one of the measures of

success in treating CLBP is when patients take over their management and no longer seek healthcare, as this can help with pain acceptance and recovery. In a systematic review of patient expectations of treatment it was concluded from eight studies that patients expect instructions or advice regarding management of their back pain, and that a lack of such instruction was a source of dissatisfaction (Verbeek, Sengers, Riemens, & Haafkens, 2004). However, there is still research that suggests that misconceptions about the modern management of CLBP (e.g. treating pain with bed rest) are common in both the general and CLBP population (Keen et al., 1999; Klaber-Moffett, Newbronner, Waddell, Croucher, & Spear, 2000).

Campbell and Guy (2007) aimed to determine the expectations of patients who continually seek re-treatment for their chronic pain, as expectations regarding pain and treatment outcome and the resultant pain experience are key determinants in how the individual will view their pain experience. Interviews were conducted for several weeks through focus groups with sixteen patients who requested secondary care after completing a multidisciplinary pain management program in the UK. Most part participants had unmet expectations, which they blamed on the inadequacy of health care professionals. They expected immediate diagnosis, treatment and cure and when health care professionals could not meet these expectations patients demonstrated distress in the form of anger and resentment toward their health care professional. These expectations fueled the sense of agency participants embodied through engaging and re-engaging with the medical system to find a cure they felt was not only possible but should be readily available. This supports Walker et al. (1999) who suggested that such unrealistic expectations often drive patients to pursue

multiple treatments which can lead to more pain than when they first began treatment. Increased psychological distress (particularly depression) resulting from unsupportive family members/friends also caused patients to re-pursue health care, thus increasing patient expectations for finding a resolution to their pain problem. Although participants demonstrated a sense of agency for seeking additional pain treatment programs, they all expressed hopelessness about the future of their pain, believing that it would persist forever.

Both May (2007) and Campbell et al. (2007) offer significant insight on the importance of self help in treating and managing CLBP. Without being guided in their self-help activities, pain sufferers are likely to persist in engaging and re-engaging in primary care services to gain access to other or repeated treatments (Campbell et al., 2007). However, when health care professionals can promote and offer CLBP patients with skills and knowledge to manage their pain on their own, they help engage the patient's agency towards more productive and long-lasting pain management techniques (May, 2007).

Summary of Qualitative Research

CLBP seems to be an experience characterized by relentless pain, frustration, and despair. Chronic pain can fundamentally alter one's lifestyle through a variety of different ways. However, there are some recurring themes throughout this review which suggest that CLBP patients have a somewhat shared understanding of their chronic illness experience. The most salient themes of the CLBP experiences from this review were inextricably linked to the medical management of pain. Feelings of uncertainty, deligitimization and stigmatization are all highly characteristic of the

CLBP experience (Walker et al, 1998; Osborn et al. 2006; Holloway et al. 2007; Crossley, 1998; Ong et al., 2004; May, 2007). These feelings negatively impact one's self esteem, creating the inner sense of being discredited, which over time can negatively affect a patient's perceived identity (Kleinman et al., 1995).

Given that the majority of CLBP sufferers are diagnosed with 'non-specific' CLBP or CLBP of unknown origin (Hainline, 1995; Nachemson, 1992; van Tulder et al., 2002a; Murphy et al., 2007); it is not surprising that CLBP patients are in a constant battle to legitimize their pain. The need to legitimize their suffering seems to be further perpetuated by the biomedical model of pain management, which endorses a pathoanatomical approach to CLBP management. This paradigm has largely persisted in the medical treatments offered to patients despite research indicating the use of multi-causal and biopsychosocial models for understanding CLBP (Corbett et al., 2007).

Given the complexity of chronic pain (Turk, 1990) it is somewhat surprising that the majority of participants had a shared understanding of the CLBP experience, as so many patients decided to focus their pain stories on such similar issues. The majority of the CLBP sufferers vehemently expressed a genuine disdain for the medical system's tendency to only acknowledge the physical aspect of pain. This contempt was partly founded upon patient frustrations with the medical system and health care professionals (Fernandez et al., 1995; Walker at al., 1999; Campbell et al., 2007). Patients continually expressed unmet expectations with pain management, while a perceived invalidating response from the medical system rendered them helpless, fighting for an identity in the medical world. These ideas all relate to Walker

et al. (1999) idea of how CLBP patients are often trapped "in the system;" a system which encourages powerlessness, helplessness and anger.

It is likely that this 'trapped in the system' (Walker et al., 1999) perception was responsible for why nearly all participants used their CLBP narratives as an opportunity to justify their suffering. Feelings of stigmatization, deligitimization, and despair based on a foundation of uncertainty regarding pain were concerns overwhelmingly expressed by nearly all CLBP patients. The homogeneity of these results advocates their validity even though many of the studies adopted unstructured or narrative style interviews to collect their data. This provides an opportunity for participants to create what Werner, Steihaug, and Malterud (2003) referred to as a 'moral plot,' where because of past skepticism and distrust; participants attempt to convince the audience of the legitimacy of their chronic illness story. Therefore, it is important to recognize the potential for such bias. However, adopting semi structured interviews place researchers in a position of increased control to manage such concerns.

It is clear that back pain research is mainly a priority in Europe, as nearly half of the studies reviewed were conducted in the UK alone. This is not surprising, given the prevalence of LBP in the UK in 1993 was estimated at 16.5 million people (Clinical Standards Advisory Group, 1994). Furthermore, since these data were reported the estimated prevalence has continued to rise, as LBP is the largest single cause of absence from work in the UK, accounting for over £11 billion in direct and indirect costs in 2000 (Maniadakis et al., 2000). What is surprising is the paucity of qualitative research on CLBP conducted in North America, as the prevalence and

financial repercussions of CLBP are also significant (Trainor et al., 2002; Anderson et al., 2006).

Another concern with the articles reviewed is that collectively they seem to focus more on interpersonal experiences than intrapersonal experiences. This is largely due to the invisibility of pain in CLBP patients (Glenton, 2006), as their behavioral manifestations are more easily perceived in their everyday lives through interactions with others (health care professionals, family, friends, and the general public) (Holloway et al., 2007). However, this seemed to de-emphasize intrapersonal health communication experiences in this review as only seven of eighteen articles provided insight on the psychological themes discussed earlier, which included: Bowman (1994b); Walker et al. (2006); Benjaminsson et al. (2007); Waters et al. (2004); Souza et al. (2006); Corbett et al. (2007) and Campbell et al. (2007). Furthermore, Osborne et al. (2007) was the only study to focus specifically on "the self" in relation to pain, even though some research indicated that medical physicians tend to adopt a Cartesian dualistic approach for treating CLBP (Osborn et al., 2006; Campbell et al., 2007; Lillrank, 2003) which can alienate the body from the self, and consequently, alienate the self from others (Osborn et al., 2006; Lillrank, 2003). It is important to incorporate both inter and intra personal experiences when studying chronic pain, while a focus on one form of communication should not come at the expense of completely ignoring another.

# Chapter 3 – Methods

## Research Context

This study represents a Maters thesis in the Faculty of Applied Health Sciences at Brock University in St. Catharines, Ontario, Canada. The rationale for studying psychological distress and CLBP is contingent upon both public and private concerns of the researcher, as CLBP is a public health epidemic, and the researcher has a private connection to CLBP through personal pain and injury. The significance and research implications of the latter will be discussed in the reflexivity/role of the researcher section. Interviews will be the primary source of data collection used for this study. It is the researcher's belief that interviews will contribute to a great deal of rich, thick descriptive data.

## Theoretical Perspective

Every researcher has a theoretical perspective, which is; "(the researcher's) view of the human world and social life within that world" (Crotty, 1998, p. 7). This perspective or worldview provides context for the research process and has inherent assumptions which are reflected through the selected methodology (Crotty, 1998). In this study, the researcher has assumed an interpretive theoretical perspective. Willis (2007) explains that an interpretive worldview adopts a relativist ontology (the nature of reality). Relativism is a way in which interpretive researchers perceive reality, as reality is something conditioned by their experiences and culture. The nature of reality is an internal or individual construction that is unique to each person. Another term that Willis (2007) uses to explain this notion is antifoundationlism, which argues

that; "there is no secure foundation that humans can use to decide what is true and what is not" (p. 49). In other words, there are no "universal truths."

Epistemologically speaking, intepretivists are nominalists, who follow a guideline of subjective experience of social reality. Willis (2007) explains this voluntarist or "free will" stance is a nondeterministic viewpoint that is characteristic of interpretive writers. The researcher of this thesis echoes Willis (2007) sentiments that human beings can determine their own behavior and that social phenomena are best studied by examining one situation in a particular context. This context can be historical or contemporary, and the understanding of this context is justified through a fundamental principle of interpretivism; verstehen (Willis, 2007). Verstehen (the German) word for understanding expresses the idea that understanding within a particular context is an honorable purpose for research (Willis, 2007). Schwandt (1994) goes on to say that lived experience is a legitimate topic of study with regard to verstehen, which reflects the researcher's choice of a phenomenological methodology.

## Methodology

According to Willis (2007) phenomenology is focused on the subjectivity and relativity of reality and continually seeks to understand how humans view themselves and the world around them. Phenomenologists investigate subjective phenomena in the belief that critical truths about reality are grounded in people's lived experience (Polit & Beck, 2007). Therefore, phenomenology describes the meaning of the experiences of a concept or phenomenon of several individuals (Creswell, 2007) and is concerned with understanding human behavior, through the subjective perceptions

and the inner realities of the individuals experiencing such phenomena (Willis 2007). Topics appropriate for phenomenology are ones that are fundamental to the life experiences of humans; for health researchers, these include such topics as the meaning of suffering. Investigating the subjective experiences of the chronically ill represents an ideal topic that is compatible with the aims and objectives of phenomenological inquiry.

There is no one approach to phenomenology as it has been subjected to change and reform by different researchers over the years due to varying philosophical assumptions (Creswell, 2007). The two broad fields of phenomenology are Edmund Husserl's descriptive (eidetic) phenomenology and Martin Heidegger's hermeneutic (interpretive) phenomenology (Cohen & Omery, 2004). Husserlian phenomenology uses a descriptive approach to seek the universal essences of an experience; features to any lived experiences that are common to all persons (Morse, 1994). The goal of Husserlian phenomenology is to achieve transcendental subjectivity[13], a foundationalist approach to inquiry that considers reality objective and independent of history and context (Allen, 1995). Heidegger's hermeneutic phenomenology emphasizes understanding (verstehen) over description, as he believed that individuals' realities are invariably influenced by the world in which they live. Heidegger used the term "being in the world" (Lopez & Willis, 2004, p.729) to explain that humans cannot abstract themselves from the world and that it is not human subjectivity that hermeneutic inquiry is focused on but, rather, what the

[13] Transcendental subjectivity: the impact of the researcher on the inquiry is constantly assessed and all his/her preconceived notions are suspended, so that they do not influence the object of study (Drew, 1999). Husserlian philosophy seeks to describe a phenomenon in its purest form; based on the descriptions provided by the informants themselves.

individual narratives imply about what a person experiences every day. In interpretive phenomenology, it is the interpretation of the narratives provided by the participants in relation to various contexts that is foundational (Lopez et al., 2004).

The theoretical perspective of the researcher, the research goals, and the topic of research for this study all help contribute to an interpretive phenomenological form of research. CLBP can have serious effects on the family, occupational, and social relations of a CLBP patient (Bowman, 1991; Walker, Holloway, & Sofaer-Bennett, 1998; Walker, Sofaer-Bennett, & Holloway, 2006; Holloway, Sofaer-Bennett, & Walker, 2007). Therefore, it is a condition that is articulated through the social lives of the chronically ill. Smith (1987) explains that a hermeneutic phenomenologist will often focus on the historical, social, and political forces that shape and organize experiences when describing the meaning of an individual's "being in the world". Furthermore, Heidegger (1962) believes that humans are embedded in their world to such an extent that subjective experiences are inextricably linked with social, cultural, and political forces. This concept is called situated freedom (Leonard, 1992), which stands in direct opposition to Husserl's (1962) radical autonomy. A concept used by descriptive phenomenologists to describe how humans are considered free agents who bear responsibility for influencing their environment and culture. Therefore, to fully understand the chronic pain experience, an interpretive perspective should be adopted.

Another philosophical assumption of Heidegger's hermeneutic phenomenology is that expert knowledge can be a useful and valuable guide for inquiry. While Husserl (1970) believed in abolishing all preconceived notions to

reach transcendental subjectivity in the search for essences, Heidegger (1962) believed this was impossible. According to Heidegger (1962), preconceived notions are what lead a researcher to pursue studying a topic in the first place, as it is a researcher's knowledge of the literature that dictates what he/she will study. Furthermore, personal knowledge, according to hermeneutic scholars, is both useful and necessary to phenomenological research (Geanellos, 2000). This study is inherently interpretive as it has clearly defined research goals based on understudied areas in CLBP literature, whereas descriptive phenomenological studies often do not have a detailed literature review or specific research questions, other than the desire to describe the lived experience of a phenomenon (Streubert & Carpente, 1999).

IPA aims to explore in detail how participants make sense of their personal and social worlds in an attempt to determine the meanings particular experiences, events, and states hold for participants (Smith et al., 2003). Meaning is central to IPA, as the aim is to understand the content and complexity of those meanings rather than measure their frequency. Smith et al. (2003) explain that while one is attempting to capture and do justice to the meanings of the respondents to learn about their mental and social worlds, those meanings are not transparently available and must be obtained through sustained engagement with the text and a process of interpretation.

There are a few reasons why IPA is an appropriate methodological choice to study the psychological experience of CLBP. Unfortunately, psychological research on chronic pain has mostly concentrated on measuring outcomes associated with the illness (Linton, 2000; Hasenbring et al., 2001; Pincus et al. 2002), while medical sociology has advocated the qualitative, phenomenological approaches to better

understand how individuals perceive their illness (Smith, 1996). However, IPA is highly related to mainstream psychology as both share cognition as a central analytic concern and both are interested in studying how people think about what is happening to them (Smith et al., 2003). Furthermore, Smith (1996) commends the idea of converging psychological research with qualitative methodologies, as much of the territory explored by phenomenologically-oriented medical sociologists is as psychological as it is sociological. Therefore, a psychological study based on IPA is both warranted and appropriate; even if it crosses the traditional boundaries of health psychology.

Secondly, CLBP patients are continually deligitimized in the medical community and stigmatized for expressing their true feelings (Walker et al, 1998; Osborn et al. 2006; Holloway et al. 2007; Crossley, 1998; Ong et al., 2004; May, 2007). Therefore, some participants may demonstrate an inability to fully disclose their true thoughts and feelings on the matter. However, IPA assumes a chain of connection between people's talk, their thinking and emotional state. IPA acknowledges that this chain of connection is complicated as people can struggle to express what they are thinking and feeling and it is the duty of the IPA researcher to interpret people's mental and emotional state from what they say (Smith et al., 2003).

Thirdly, the psychological problems associated with CLBP are typically articulated through the personal and social lives of each patient (Holloway et al., 2007). IPA aims to explore in detail how participants make sense of their personal and social worlds, thus, it is inherently advantageous for such research.

Finally, IPA's applicability for understanding the chronic pain experience is evidenced by its use in contemporary CLBP research, particularly in the UK (see qualitative literature review), as it is utilized more than any other form of phenomenological research. For all these reasons, this study will adopt the approach of IPA as explicated by Smith et al. (2003).

## Role of the Researcher/Reflexivity (Partly Written in 1st Person)

Impact of "the self" on the study

Guba and Lincoln (2005) define reflexivity as "the process of reflecting critically on the self as a researcher," (p. 210). "The self" in this case, has serious implications on the entire research process. My personal experiences with CLBP have a direct impact on the purpose, theoretical perspective, and methodology of my study. I experienced CLBP for four consecutive years (2004-2008). Although, the pain has since subsided, I will always have an inherent interest in the matter. As alluded to in the introduction, the rationale for the proposed research is incumbent upon the prevalence of CLBP in western society, its financial repercussions and burden on public health care systems, in addition to a need for an improved understanding of the psychological response to pain. However, my personal psychological battle with chronic pain has inspired me to learn more. Four years of CLBP lead to continuous medical engagement and a long-term physical battle that helped establish a psychological obsession with managing pain. The nature of my CLBP experiences in relation to other CLBP patients I have spoken with over the years has given me formidable insight into the different ways CLBP can impact ones identity. These experiences have proven to me that each person has a unique psychological response

to pain; therefore, I believe the psychological response to CLBP is best understood through contextual, rather than universal meanings. This helps explain the interpretive theoretical perspective inherently guiding this study and the highly idiographic methodology through which the research will be conducted. Therefore, it is clear that my role as the researcher has significantly impacted the purpose, nature, and design of this study.

Creativity in Methods-A role of the Researcher

Creswell (2007) states that it is the role of the researcher to decide how and in what way his/her personal understandings will be introduced into the study. I am both theoretically and personally familiar with the psychological research themes (depression, fear-avoidance, catastrophizing, anxiety and somatization) outlined earlier in this proposal. My personal CLBP experiences have been associated with all five concepts in one way or another and I have dedicated considerable time researching different psychological influences on CLBP through a review of the literature. Therefore, I have clearly developed pre conceived notions on the relationship between CLBP and psychological distress. Some forms of descriptive phenomenology demand that these inherent presuppositions be suspended prior to analysis through phenomenological reduction (e.g. transcendental phenomenology). However, the true goal of IPA is to interpret the meaning of the participants' experience (Smith et al., 2003), rather than capture the essential structures of a phenomenon as they appear in consciousness (Giorgi, 2003). Such an interpretive approach to phenomenology makes it impossible for the researcher to become separated from the text (van Manen, 1990). Therefore, I plan to use my preconceived

notions and personal understanding of the CLBP experience to improve my hermeneutical prowess, in an attempt to interpret the meanings of each participant's CLBP experience to the best of my ability.

The Interview

The interview is a highly personal and dynamic process and there are certain roles that specifically apply to this study. Polkinghorne (1983) explains that during the interview process, the researcher/participant interaction should take place within the context of a relationship. Polkinghorne (1983) also says that an environment of safety and trust needs to be established at the outset and maintained throughout the project. It is imperative that the researcher establish such an environment, as the discussion will involve personal thoughts and feeling associated with chronic pain.

## Data Collection Procedures

Sampling Criteria

Purposeful sampling was used to select information rich cases that would lead to an in-depth understanding of the phenomenon in question. Polkinghorne's (1989) recommends selecting a sample size that is no more than twenty-five and no fewer than five, when conducting phenomenological research. Meanwhile, IPA typically uses very small sample sizes as Smith et al. (2003) recommend five to six participants as a reasonable sample size for a student project. However, these are only recommendations, as Smith et al. (2003) make explicit that all IPA researchers have creative control over the methodological procedures of their study. It is expected that five participants would not create enough data to thoroughly examine similarities and differences between participants. However, fifteen to twenty five participants may

have produced an overwhelming compilation of data. Therefore, the population size for this study was originally estimated to be twelve to fourteen CLBP patients. These figures reflect Polkinghorne's (1989) recommendations but were also based upon personal communications with experienced qualitative researchers on the thesis committee; including Dr. Jarold Cosby and Dr. Maureen Connolley.

Participant selection primarily adhered to specific criteria that coincided with relevant health care and research concerns. The first was a demographic focus on incidence of CLBP; which is highly prevalent in the adult population (Chou et al., 2007; Poiraudeau, Rannou, & Revel, 2007). The second was a focus on studying adults who have experienced sick leave due to CLBP, as indirect costs related to days lost from work are substantial (Luo et al., 2004; Maniadakis et al., 2000). And finally, the third was a need to investigate the description of pain experiences for both men and women, as it has been suggested that women report more severe pain, more frequent pain, pain of longer duration, are more diffuse in describing pain symptoms and may be more prone to report a pain problem influenced by psychological factors as oppose to an somatic pain symptom (Dao & LeReche 2000; Edwards, Haythornthwaite, Sullivan, & Fillingim, 2004; Raak & Wahren, 2006). CLBP was defined as continuous LBP lasting for at least three months (van Tulder et al., 2002b). In compliance with the primary sampling stipulations and the aforementioned public health/research concerns; six to seven male and six to seven female adults (between the ages of 20-60 years old), who had suffered from LBP for at least three months were to be selected for this study. At least six to seven of the participants were to have experienced sick leave attributable to LBP (for at least seven consecutive days)

(Hartman, Vrielink, Huirne, & Metz, 2003) and all participants had to be upwardly mobile and physically capable of partaking in and transporting themselves to and from the interview. Such a heterogeneous sample also ensured an expanded and vast repertoire of CLBP experiences (e.g. male & female experiences, young adult & middle-aged adult experiences, sick leave & non sick lave experiences etc) so as to improve the capacity for articulating greater conceptual meanings.

Sample Recruiting Procedures

All participants for the study were recruited from the general public of the Niagara region by the researcher through word of mouth and by referrals from other people. In other words, either the researcher personally contacted people he knew to be suffering from CLBP or the researcher contacted those people that another person had suggested would be a good candidate for the study. The researcher made initial contact to each participant via telephone. The phone numbers of each participant were already available to the researcher or provided by the contact that referred the potential participant. All people who referred a potential participant were informed and aware that their names would be disclosed to the potential participant. In the initial contact with a potential participant, the researcher introduced himself and the basic details of the study (see data manual – section B). If the potential participant expressed a desire to learn more about the study, they were screened for their ability to fit the requirements for participation and asked to provide a home mailing or email address in which further details could be delivered to. This included both a letter of invitation and an informed consent form (data manual section C; data manual section D).

All potential participants preferred the use of email, so the researcher emailed further details in the form of a letter of invitation and an informed consent form to any participant who wanted to learn more about the study. These forms helped to fully explain the purpose and nature of the study, the requirements of participation, and the rights of each potential participant would be entitled to. These forms were intended to assist the potential participants in making a well informed decision on whether or not they would participate. Although potential participants were informed that the researcher would be re-contacting them in three to five days to determine if they would be participating (data manual section B), all potential participants proceeded to contact the researcher via email within one to two days of the initial contact. After contacting the researcher via email to confirm their interest in participating, the researcher re-contacted each participant by telephone to confirm their interest in participating, set up an interview time, and remind them of their rights to free and voluntary participation, as well as confidentiality and anonymity (data manual section E). After setting up an interview time, all participants were immediately emailed a confirmation letter and map of Brock University (data manual section F; section G).

Although each participant agreed to participate in the study within twenty-four to forty-eight hours of initial contact from the researcher, they were informed that they would have three to five days to make a decision on whether they would be participating. If a potential participant would not have decided on whether or not he/she would be participating following the three to five day period, their position to volunteer would have become available to another person. Therefore, their position to

participate may have been occupied by another person. Although this was not the case for any participant, the researcher created a third telephone script to prepare for the likelihood of such an occurrence (data manual section H).

Sample

The first nine participants' engaged by the researcher agreed to participate in the study. All participants were Caucasian and in the age range of twenty to sixty years. The average years of CLBP experienced by all participants was twenty-one and six of the participants had low back surgery. Following the initial iteration of the analysis of these nine participants two additional participants were selected for interview. This allowed the researcher to perform an original extensive analysis on the first 9 interviews, and then test the model and concepts with 2 additional interviews. The recruitment of these participants followed the same protocol sampling recruiting procedures as described above. Table 1 (pictured below) outlines the demographical and pain-related characteristics of each participant; in addition to interview time and location.

Table 1
Participant Bios

| Case # | Pseudonym | Age Range | Gender | Race | Occupation | Sick Leave | Surgery | Episodes of intolerable LBP | Duration of CLBP | Interview time | Interview Location |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 1 | Michelle | 20-30 | Female | Caucasian | Student | No | No | 3 | 4 years | 46 min | Brock University |
| 2 | Monique | 30-40 | Female | Caucasian | High school teacher | Yes | No | 2 | 5 years | 46 min | Brock University |
| 3 | Maureen | 30-40 | Female | Caucasian | Legal clerk; receptionist; self-employed | Yes | No | 2 | 22 years | 43 min | Brock University |
| 4 | Steve | 20-30 | Male | Caucasian | Student | No | No | 2 | 3 years | 42 min | Brock University |
| 5 | Edna | 40-50 | Female | Caucasian | Beer Store Clerk; Literacy coach | Yes | Yes | 3 | 18 years | 51 min | Home Address |
| 6 | Joanne | 50-60 | Female | Caucasian (English) | Office manager, now retired | No | No | 3 | 40 years | 1hr 1min | Home Address |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 7 | Marissa | 50-60 | Female | Caucasian | Retired Nurse | Yes | Yes | 3 | 45 years | 55 min | Brock University |
| 8 | Gary | 50-60 | Male | Caucasian | Retired elementary school teacher | Yes | No | 3 | 38 years | 53 min | Brock University |
| 9 | Brittany | 20-30 | Female | Caucasian | Student | No | No | 2 | 7 years | 46 min | Brock University |
| 10 | Jacob | 50-60 | Male | Caucasian | Associate Dean | No | No | 7 | 35 years | 61 minutes | Brock University |
| 11 | Keith | 30-40 | Male | Caucasian | Grocery Store Manager | Yes | No | 4 | 12 years | 40 minutes | Home Address |

Average interview time: 50 minutes; Average pain duration: 21 years

## Ethics

The researcher conformed to all ethical guidelines outlined in the Tri–Council Statement: Ethical Conduct for Research Involving Humans (TCPS) as explicated in section III: 8 of Brock University's Faculty Handbook pertaining to research ethics. The researcher completed and submitted an application for ethical review of research involving human participants to Brock University's Research Ethics Board (REB). This study was reviewed and received ethics clearance through the REB at Brock University on December 12th, 2008 (08-119 COSBY/AYMAR) (for a copy of the REB letter of approval, please refer to section A of the data manual). All names and contact information colleted were only used for the sole purpose of this research protocol. All identifying information was only known by the researcher and he followed all REB protocols to ensure confidentiality and anonymity of the potential participants. Identifying information was not shared with any members of the research team and an anonymity protocol (pseudonyms) was used to ensure there were no linkages between patient identifiers and the interview data. Patients were clearly informed that all involvement was strictly voluntary. All patients had the right to refuse participation at any time. They were verbally informed of this right during their initial contact with the researcher, again during the second telephone recruitment

phone call and once immediately prior to the interview itself. Participants were also informed of this right in writing in the informed consent form and in the confirmation letter.

## Data Collection

### Interviews

In-depth interviews are typically the primary source of data collection used for all forms of phenomenological research (Creswell, 2007). Each participant completed one in-depth interview, lasting anywhere from forty-five to sixty minutes; the average interview time was fifty minutes. All participants signed two copies of the informed consent form prior to the interview; one form for their own record (which they received initially through email) and one form for the researcher's records (which was provided at the interview). No interview commenced until the participant signed both informed consent forms.

Eight of the interviews were conducted at Brock University's Health Decisions Lab located in Welch Hall (WH 145), a private room at Brock University, located at 500 Glenridge Avenue in St. Catharines, ON, Canada. The room was secured by a code lock and was off limits to all other student body or faculty during interview time. There were no windows in the room to allow for outside distractions. This ensured total privacy for both the interviewer and the interviewee. The remaining three interviews were conducted at the respective households of the participants. This option was available to participants upon request and in the case of these participants, although they were mobile, their conditions made them apprehensive to drive to Brock University. In these 3 cases, the interview rooms

selected by the participants and agreed upon by the researcher were both quiet and private, as all 3 interviews were free from distraction. All interviews were audio recorded and transcribed verbatim by the researcher (for a copy of each interview transcript – see appendix A). During the interview, the audio recorder was placed in-between the participant and the researcher. The audio digital recorder was a Sony Stereo IC Recorder (ICD-SX57DR9) with high quality stereo recording, so participants were encouraged to speak in a position they felt comfortable (e.g. sitting, standing, pacing, etc). Before each interview commenced, the participant was provided the option of taking a five-minute break at any time throughout the interview. However, no participant required a break.

Interviews were semi structured around critical events in relation to the chronic pain experience (e.g. the initial injury, the diagnosis, pain management etc). These critical events were used to help facilitate the "story telling process" of the interview but also provided the researcher with opportunities to focus on psychological issues that participant's may have been hesitant to address on their own. As the interview and each participant's story progressed the researcher began to rely more on the use of reflective questions. Again, these questions were intended to indirectly address psychological issues that participant's had thus far been hesitant to discuss, while still allowing for new and unique details on the CLBP experience to emerge. Some examples of reflective questions included were:

- 'How often do you think about your low back?'
- 'Can you describe your thoughts and feelings during times of pain?'
- 'Has CLBP changed or affected how you perceive yourself?'

    - 'If so, how? If not, why don't you think it has?
- Has CLBP changed or affected how others perceive you? If so how? If not, why don't you think it has? Can you please describe in detail how CLBP has impacted your lifestyle?
- What does CLBP mean to you?

The researcher also prepared questions that specifically addressed salient psychological issues (e.g. Can you describe if and how fear of pain has affected your life?). This direct form of questioning was used during each interview if participants failed to address specific topics of concern for the researcher. For a complete list of questions, please see the interview guide in Appendix B.

These interviews worked to establish rich and detailed emergent data on the subjective experiences of the participants, while still maintaining an internal focus on the psychological reaction to pain, including the five psychological research themes (depression, catastrophizing, fear-avoidance, anxiety and somatization) previously outlined in the introduction. Another commonality was that the interviews unfolded much like a chronological story of CLBP. All participants began their story from the initial injury or onset of pain, which then continued through the acute and chronic phases of LBP, and finished at the present day of their lives. Each interview also utilized questions structured around critical events and reflective concepts. It is imperative to understand that these critical events/reflective concepts were used primarily as a guide for the researcher to rely on to facilitate rather than dictate the interview. However, for all these similarities, no two interviews were the same. The order in which different psychological factors were addressed varied and

subsequently the order in which questions were asked changed from interview to interview.

Gaining access into the personal and social world of the participant is an objective of an IPA (Smith et al., 2003). Thus, the interviewer adopted specific strategies to generate in-depth and meaningful answers in an attempt to be fully immersed into the personal and social worlds of the participants. One of these techniques was "funneling" (Smith et al., 2003, p.60), as the researcher would elicit participants' general views on certain aspects of the CLBP experience before getting into more specific questions of particular concern. For example, initially questions generally addressed one of the critical issues/events of the CLBP experience. The researcher would then get more in-depth into each issue or event, specifically focusing on each participant's behavior during this time, their emotional reaction or response to the event, as well as their attitudes, thoughts and feelings regarding the experience and its implications.

Another strategy the researcher employed to gain insight into the emotional reactions to specific events or aspects of CLBP was probing. The nature of this probing was very specific, as the most frequently used and successful probe to help further understand a participant's thoughts or feelings on a subject was: "How does that/did this make you feel?" The researcher would also probe to get a sense of what each participant perceived others thought or felt about a particular subject (e.g. 'What do other people think of that?' 'How do others feel about that?') These strategies combined to provide insight into the personal and social lives of each participant along different points of their chronic pain experience. This was critical as IPA aims

to interpret and understand both the personal and social worlds of each participant (Smith et al., 2003).

## Data Analysis

Looking for Themes in the First Case

Following the guidelines of IPA as explicated by Smith et al. (2003), cases one to eight were examined one at a time. Case number nine was analyzed differently and will be discussed later. All cases were analyzed in the order they were interviewed (case one, case two, etc). When taking on the first case, the initial transcript was read over a few times to allow the researcher the opportunity to familiarize himself with the data. The researcher then made bold font notes of anything interesting or significant about what the respondent had said. The nature of these bold notes ranged from comments about the language used by the participant, to simple paraphrasing, to similarities and differences to preliminary interpretations (Smith et al, 2003). This process was carried out for the entire first transcript. Then the transcript was read over again, but this time the researcher documented emerging theme titles based on the information recorded in bold notes. Here the initial notes were transformed into concise phrases or expressions that aimed to capture the essential quality of what was found in the text (Smith et al., 2003). These themes moved to a higher level of abstraction and involved more psychological terminology. As Smith et al. (2003) state; "the skill (of this step) is to find expressions which are high level enough to allow theoretical connections within and across cases but which are still grounded in the particularity of the specific thing said," (p. 68.). The transformation of initial notes into themes continued until the entire transcript had

been analyzed, as no parts of the interview were skipped (for a copy of the initial analysis of each transcript – see Appendix C).

Connecting the themes

After the entire transcript had been initially analyzed, all resultant themes were listed categorically, as the researcher looked to make connections between the various themes. Following Smith et al. (2003) procedure of single case analysis, those themes that were similar were clustered together. All individual themes were listed with a number in parenthesis to indicate the page of the transcript where the theme had come from. All clusters were comprised of at least two themes. What resulted was a list of theme clusters (for a copy of each participant's list of theme clusters – see Appendix C).

Clusters of three or more themes were typically articulated into one overall theme. The process through which this occurred required much attention and focus. Typically, the researcher would gather quotes in the transcript from which the original themes had been derived and list them altogether. He would examine each quote individually and assign each of them a descriptive title that best described what the participant was saying. Essentially, what was once a cluster of themes was now a cluster of quotes labeled by descriptive titles. Next, the researcher examined all quotes and their descriptive titles in relation to one another to help articulate a final theme title that best represented those quotes. This was the most difficult procedure of the single case analysis, as the researcher engaged in a highly iterative process of continually checking to ensure that the descriptive titles assigned to each quote and the final themes describing each cluster of quotes fit with the original data from the

interview transcript. This involved a close interaction between the researcher and the text, as the researcher relied on his/her interpretive resources to make sense of what the person was saying, while constantly checking his sense making against what the participant actually said (Smith et al., 2003). What resulted from this procedure was a final theme title, a definition of the final theme title, a list of descriptive titles to support the final theme (otherwise known as supporting themes) and verbatim extracts from the interview transcript to support each descriptive title/supporting theme. Each verbatim extract was identified by three numbers. The first identified the case/transcript number, the second identified the page number of the transcript from which the quote was extracted and the third identified the line number which the first word of the quote could be located on, within whatever page it was extracted from. For example, a quote from line number thirty-four, of page number six, in transcript number one would be identified as (1; 6; 34).

The researcher carried out this entire procedure for each theme cluster. Therefore, the more theme clusters a case had the more final themes it was assigned. Each case was assigned four to six final themes. However, in some cases the researcher felt intrigued by certain ideas participants expressed that were not included in theme clusters. These ideas often were only expressed once or twice by the participant but offered critical insight the researcher conceived may be pertinent for understanding the psychological and emotional reaction to CLBP. Therefore, the researcher documented such ideas in the list of final themes for each case in a separate section entitled "interesting ideas not included in themes." These ideas were

not categorized with any others and were represented by a verbatim quote and descriptive title (to see a copy of the final themes for each case – see Appendix C).

Continuing the analysis with other cases

The exact same procedure was then conducted for the rest of the cases (up until case nine) as each account was given its own unique analysis. However, the final and supporting themes from case one were used to inform the analytical proceedings for case two, while these themes were then used to inform case three, and so on. Referring to the final and supporting themes of previous accounts provided the researcher with a reference point to help recognize ways in which new cases were similar but also different (Smith et al., 2003). This style of analysis honors Heidegger's hermeneutic circle of questioning and understanding, as pre conceived notions of a subject help us pose intelligent questions about a topic we are trying to understand, but it is the answers to the questions we pose which force us to revise the presuppositions with which we began (Moran, 2000).

Individual and Cross Case Summaries

After the first four cases had been analyzed, the researcher began to individually summarize the final themes of each case analysis (excluding case nine). For this, each final theme title and its definition was listed and labeled by two numbers. The first number represented the case number and the second represented the theme number. For example, final theme number two of case number one was labeled as (1:2)[14]. Below each final theme title and its definition was a list of all the supporting themes. However, the verbatim quote each supporting theme represented

[14] Those ideas included under "interesting points not included in themes" were identified by the letter X.

was not included in the summary. Rather, the researcher summarized the quote in his own words, which he then italicized and placed in parenthesis beside the supporting theme title. These quote summaries were again labeled by the case number and final theme number they represented from (for a copy of the final theme summaries of each case – see Appendix C).

The researcher then categorically placed all the supporting themes and their summarized quotes into a cross case summary. Much like the original single case analysis procedure, similar supporting themes were clustered together. The idea of the cross case summary was to help make connections between different final themes of each individual case. However, the supporting themes ultimately represent the final themes of each individual case, as without the supporting themes there can be no final themes. Also, each final theme had approximately three to six supporting themes that were all unique and illustrated the final theme from different angles, thus, in its entirety. Therefore, comparing supporting themes of individual cases as opposed to final themes created more opportunity for making unique connections between the cases.

Following the analysis of case four, each successive single case analysis was immediately summarized upon its completion, as each new supporting theme was strategically placed into similar clusters of supporting themes within the cross case summary. Eventually, as clusters of supporting themes increased, they were given titles of their own (these were bolded and underlined). In some instances the researcher provided these theme titles with definitions, but this was not always the case. Essentially, themes that once supported the final themes of individual cases now

supported themes represented by multiple cases. The cross case summary of supporting themes continually changed as the analysis of each case progressed. The researcher was continually looking to make connections between and combine supporting theme clusters, while those supporting themes that did not fit into theme clusters were being dropped. Therefore, the development of the cross case summary helped inform the analysis of each new case and the analysis of each new case helped remodel the cross case summary. A final edition of the cross case summary can be found in Appendix D. This summary documents all supporting themes of each single case analysis from case one to case eight that had been selected to be clustered into unique categories.

However, one new and unique idea was discovered in case number seven. This final theme was entitled: "Planning life to accommodate pain" and referred to how participant number seven continually engaged in a series of procedures to accommodate pain in his daily life. This was accompanied by a sub theme entitled: "Readjust movement patterns to avoid pain/accommodate problem," which explained how the participant had to reorganize his locomotive patterns through altered preparatory thought and physical movement. These themes offered a preliminary conceptualization of a particular idea the researcher had pondered throughout the analysis of previous cases, but had not yet made explicit. This was mainly due to the difficulty in identifying or defining exactly what the idea or theme was. After this initial conceptualization the researcher re-engaged each interview transcript (case one to case six) to document the prevalence of this new idea in each of the previously

analyzed cases, while attempting to re-conceptualize the new theme. This was done before the single case analysis of participant number eight commenced.

Following the re-examination of case one and case two this new theme was re-conceptualized by the researcher by establishing both a new theme title and theme description. "A permanent pain consciousness" was the new theme title configured by the researcher and its preliminary conceptualizations, along with empirical evidence, can be found in the "Final Themes" section of both case number one and case number two (see appendix C). "A permanent pain consciousness," as explicated in the "Final Themes" section of case one and two, was accounted for by the researcher in all further cases prior to case seven (cases three to six). Therefore, the theme title "A permanent pain consciousness" was added to each case's (cases three to six) list of final themes (see Appendix C), with empirical evidence supporting the theme documented at the bottom of each "Final Themes" section. In the single case analysis of participant number eight "A permanent pain consciousness" was documented as a final theme in the initial analysis. Due to the retrospective nature of its design "A permanent pain consciousness" and all supporting theme titles accompanying it throughout each single case analysis were not included in the cross case summary.

Cross Case Analysis

Following the analysis of case number eight, the next iteration of analysis was the conceptualization of cross case themes based on the supporting theme clusters of the cross case summary. Six specific theme clusters had emerged in the summary. They included clusters entitled: isolation, depression, emotional trauma during intense bouts of LBP, living with a damaged body/injured self, lived fear based on the

perceived consequences of injury/intense pain, and a pain created by the body and expressed by the mind. These cross case theme clusters represented the foundation for the development of the overall cross case themes of this study. However, each theme cluster and all supporting themes within each cluster required a special analysis of their own, as they had not yet been conceptualized into clear, succinct, unique, and meaningful themes just yet. Therefore, the researcher embarked on yet another analytical mission, as he looked for patterns and connections within and between supporting theme clusters. This ultimately lead to the development of four overall cross case themes, which included;

- Living alone with an injury: Isolated from others and by others;
- Depression based on feelings of physical and psychological helplessness
    - (sub theme) Increased frustration based on an inability to receive medical help/ support;
- Lived fear based on the perceived consequences of anticipated extremely-severe LBP;
- and A self concept defined by pain – "Low back pain is a part of who I am" (sub theme) Living with a weakness.

The process through which six cross case supporting theme clusters were translated into four overall cross case themes was iterative and rigorous. First the researcher looked for any connections between supporting theme clusters. It was determined that the supporting theme clusters entitled: "depression" and "emotional trauma during intense bouts of LBP" were related and should be examined together. Then it was determined that the supporting theme clusters "living with a damaged

body/injured self" and "a pain created by the mind and expressed by the body" were related and should be examined together. All other theme clusters were examined individually.

Next, the researcher looked for connections within supporting theme clusters. During this process the researcher worked inductively, examining the original verbatim quotes that all supporting themes of one particular cluster were based on. The researcher looked for patterns and commonalities between supporting themes/verbatim quotes to find possible connections that would best articulate an overall theme idea. In some instances, the researcher would re-examine particular quotes within the transcripts they had originally been extracted from. This provided the researcher the opportunity to re-examine the meanings of particular verbatim quotes within the context they had been expressed in by the participant. In some instances, the researcher re-articulated the meanings of particular quotes and subsequently altered the supporting theme titles the quotes had originally been assigned. The researcher also revisited interview transcripts and single case analysis documents to find additional supporting themes to help augment premature theme ideas in need of additional empirical support. Inevitably these proceedings led to the formation of four unique cross case theme themes. The researcher clearly defined each theme and selected one piece of empirical evidence from each case to represent each theme. In some instances, these quotes were organized under specific subheadings which dictated how each piece of empirical evidence related to the final theme in which they represented (these quotes and subheadings were later used to help facilitate the narrative account of each theme).

Appendix E documents this entire process. Final cross case themes are numbered in the order in which they were analyzed. As previously mentioned "A permanent pain consciousness" was not included in the cross case summary. Therefore, rather than working with supporting theme clusters, the researcher gathered all supporting empirical evidence from each single case analysis before engaging in the same inductive and interpretive procedures to help develop and articulate a fifth overall theme. "A permanent pain consciousness" was actually the first theme to be articulated, therefore, it is documented as the first overall cross case theme in Appendix E.

Verifying the themes

The researcher performed a partial individual case analysis for participant number nine. This analysis was concerned with testing the prevalence of the five cross case themes that had emerged from the cross case analysis, while searching for data that could possibly compromise the integrity of such themes. All five themes, including: "A permanent pain consciousness;" "Living alone with an injury: Isolated from others and by others;" "Depression based on feelings of physical and psychological helplessness (sub theme) Increased frustration based on an inability to receive medical help/ support;" "Lived fear based on the perceived consequences of anticipated extremely-severe LBP;" and "A self concept defined by pain – "Low back pain is a part of who I am" (sub theme) Living with a weakness" were accounted for in case number nine. Verbatim quotations supporting each final cross case theme were extracted from the interview transcript and added to each theme's list of empirical evidence in Appendix E. Furthermore, no new data that compromised the

integrity of these themes was accounted for by the researcher. Therefore, case number nine further validated the cross case thematic analysis previously outlined. A copy of the interview transcript for case number nine can be found in appendix A, while a list of final themes for case number nine can be found in the archive of case analysis documents in appendix C.

Writing up the analysis

This was the final section of the analysis and it was concerned with moving from the final themes to a write up and final statement outlining the meanings inherent in the participants' experiences (Smith et al., 2003). This stage was concerned with translating each of the final themes into a narrative account, as themes were to be explained, illustrated and nuanced. Smith et al. (2003) explain that this final section distinguishes clearly between what the respondents said and the analyst's interpretation or account of it. However, before writing this section, the researcher spent much time thinking of and interpreting ways to conceptualize and present each of the final themes created from the cross case analysis as unique yet interconnected ideas. During this time the researcher first decided that, "Depression based on feelings of physical and psychological helplessness" and "Increased frustration based on an inability to receive medical help/ support" were to separated as two distinct themes, as they represented separate ideas. The researcher later changed the theme title "Depression based on feelings of physical and psychological helplessness" to "Depression based on feelings of helplessness" as this was more reflective of the theme's true meaning. The researcher decided to collect additional data through two extra interviews with participants 10 and 11; Jacob and Keith. These additional

interviews were intended to find data that supported existing themes, help further understand or articulate existing themes in new ways, directly oppose existing themes and/or provide any unique ideas related to the topic of investigation not yet made explicit in existing themes. A partial analysis of these interviews and their contribution to the updated analysis are documented in appendix C from page 577-590. Finally, a component of the permanent pain consciousness theme (susceptibility) was translated into a new and independent theme, entitled: "Personal susceptibility to pain," so that seven themes existed in total (these themes are organized in table 2 in the next section). The sub theme "Living with a weakness" was then transferred from its original theme "A self concept defined by pain – "Low back pain is a part of who I am" to the new theme "Personal susceptibility to pain," as perceived susceptibility and perceived weakness were considered more compatible. Throughout the process of re-engaging the data, altering themes and collecting additional data, it became apparent that each participant's experience of CLBP was characterized by everyday LBP that participants considered manageable or tolerable, interrupted by recurring episodes of devastating LBP that left participants incapacitated for as long as it persisted. Furthermore, the researcher realized that each of the themes was specifically related to these varying forms of pain. Thus, the researcher decided to describe the CLBP experience as persistent tolerable LBP interrupted by periods of ILBP (this idea is discussed more thoroughly in the following section) to help portray each theme as a reaction to a specific type of pain.

## Chapter 4 – Results

### Everyday Tolerable LBP vs. Periodic Intolerable LBP

Participants would experience persistent and continuously noticeable LBP everyday. During this time they exhibited no sign of physical disability and were able to function at a somewhat normal capacity, as all participants had become accustomed to living with such pain. This was a dull and dormant pain that would fluctuate in severity (temporarily increase or temporarily decrease), however, it was always controllable and manageable; therefore, this type of pain will be referred to as "tolerable low back pain" (TLBP) for the remainder of the study. In addition to living with TLBP, all participants described multiple experiences with a pain they described as excruciatingly painful. This pain was extremely debilitating, as it rendered participants physically helpless and stripped them of their functionality for as long as the pain would persist. Such pain would persist anywhere between a few days to slightly over a month's time. However, one participant reported experiencing a period that persisted for as long as eight months. This pain was uncontrollable and unmanageable and will be referred to as "intolerable low back pain" (ILBP) for the remainder of the study. Following periods of ILBP, pain severity would gradually subside to TLBP that participants had become accustomed to throughout their everyday lives. Therefore, the CLBP experience was characterized by persistent TLBP interrupted by periods of ILBP.

The terms "TLBP" and "ILBP" are not intended to dichotomize two levels of LBP intensity. Rather, they are intended to dichotomize patient perceptions of pain

within the CLBP experience. For example, no participants expressed the idea that to experience CLBP was to experience LBP of moderate or extreme severity. Rather, participants conceptualized CLBP as a life with LBP that was controllable, manageable, and tolerable or uncontrollable, unmanageable, and intolerable. In this sense, TLBP and ILBP represent subcomponents of CLBP, as CLBP is the experience of continuous TLBP interrupted by periods of ILBP; it is either one or the other. Furthermore, patient reactions to CLBP were specifically related to and contingent upon these varying forms of TLBP and ILBP. Thus, conceptualizing CLBP within the framework of TLBP and ILBP will help facilitate a clear explication of patient reactions to CLBP in a way that is meaningful to them.

As previously alluded to, each participant eventually succumbed to a lifelong engagement with TLBP. In some cases, the initial onset of this pain was a result of an experience with ILBP, while in other cases it gradually developed to initiate the CLBP experience itself. Regardless, once TLBP was initiated, it persisted. The persistence of such pain was greater for some than others, as some participants did recall pain free episodes. However, these times were few and far in-between and TLBP was generally a permanent fixture in the lives of each of the participants. Following an episode of ILBP all participants expressed a desire to avoid further recurrences of such pain, therefore, they attempted to be permanently conscious of ways to avoid recurrences of such pain through the pursuit of what theme # 1 describes as "A permanent pain consciousness." However, as theme # 2: "Personal susceptibility to pain (sub theme: 'living with a weakness')" will demonstrate, all participants lived with TLBP under the impression that they were likely to experience

a recurrence and that the lower back was a weakness which accentuated their susceptibility to experience ILBP. Furthermore, the perceived susceptibility to experience ILBP served as the foundation for each participant's desire to avoid a recurrence, both of which were reinforced following the recovery of successive recurrences of ILBP.

All participants ILBP. The duration of such pain varied from experience to experience, but typically persisted anywhere between a few days to one month, which directly related to the development of theme # 3: "Depression based on feelings of helplessness." The frequency of such experiences also varied, as participants endured periods of ILBP within a general range of three to four times each, with an average of three. The uncertainty of such pain made for a set of unique experiences among each of the participants. The onset of pain was always unexpected, the duration in which it would persist was unknown, the intensity of pain was consistently high but the thought of progressive agony was always a concern, while the time in-between pain episodes were variable. Such uncertainty made it difficult for participants to establish clear pain patterns during periods of ILBP. Without clear pain patterns or pain expectations participants could not establish and rely on consistent pain management strategies, the affects of which will be discussed in theme # 4: "Frustration with the medical system during times of ILBP." Essentially the uncertainty of ILBP contributed to the uncontrollability of pain, which inevitably created an "intolerable" experience for each participant. Exposure to such experiences planted a seed of fear in the minds of participants which will be discussed in theme # 5: "Lived fear based on the perceived consequences of anticipated ILBP."

Living a life of chronic pain characterized by persistent TLBP interrupted by periods of ILBP led to developmental changes in the lives of each participant. As theme # 6 "Living alone with an injury: Isolated from others and by others" will demonstrate, each participant felt more isolated as their CLBP progressed. Furthermore, prolonged CLBP progressively altered each participant's self-concept, as explicated in theme # 7: "A self-concept defined by pain – "Low back pain is a part of who I am." Table 2 outlines each theme, including theme descriptions and notes on theme development. Themes are numbered only for the convenience in identifying them.

Table 2
Outline of Themes

| Theme # | Theme name | Theme description | Theme Development |
|---|---|---|---|
| 1 | Permanent pain consciousness | -Participants are continually vigilant of bodily movements<br>-Continually anticipating and preparing for potentially painful stimuli.<br>-All based on a desire to avoid ILBP | -Established following recovery of initial episode of ILBP<br>-Reinforced following recovery of each recurrence |
| 2 | Personal susceptibility to pain | -All participants felt extremely susceptible to experiencing a recurrence of ILBP | -Established following recovery of initial episode of ILBP<br>-Reinforced following recovery of each recurrence |
| Sub theme | Living with a weakness | -The lower back is perceived to be a weakness<br>-Contributes to feelings of susceptibility | -Developed over CLBP experience |
| 3 | Depression based on feelings of helplessness | -Both the loss of physical functioning and the uncertainty of pain duration during bouts of ILBP combined to create feelings of helplessness, which ultimately produced a depressing experience | -Reaction to ILBP that recurs during successive occurrences |
| 4 | Increased frustration based on an inability to receive medical help/ support | -No participants were able to establish a successful routine for managing ILBP within the medical community, which often lead to increased feelings of frustration and disdain for the medical system | -Reaction to ILBP that recurs during successive occurrences |
| 5 | Lived fear based on | -All participants lived in fear of re- | -Reaction to ILBP that |

| | | | |
|---|---|---|---|
| | the perceived consequences of anticipated ILBP | experiencing ILBP<br>-This fear was based on what they perceived the consequences of an anticipated recurrence with ILBP would be | persists throughout CLBP experience<br>-Accentuated with successive recurrences |
| 6 | Living alone with an injury: Isolated from others and by others | -All participants directly contributed to their own isolation and loneliness as they were reluctant to admit or express their suffering<br>-Others contributed to each participant's isolating experience as well through a lack of understanding | -Developed over CLBP experience |
| 7 | A self concept defined by pain – "Low back pain is a part of who I am" | -All participants expressed the idea that living with CLBP ultimately modified their self-concept, as all participants integrated their pain to represent a part of who they had become and likely would be for the rest of their lives | -Developed over CLBP experience |

**Theme # 1 – Permanent pain consciousness**

Living with CLBP fundamentally altered the conscious thought and behavior of all the participants. Following their initial experience with ILBP, as TLBP persisted; all participants were anxious about experiencing a recurrence of ILBP as they feared the consequences of such pain (see theme four). Therefore, participant's established a concern for avoiding the onset of another episode of ILBP. This forced participants to be continually aware of their lower backs and any potential sources of ILBP. Their dedicated pursuit of avoiding a recurrence of ILBP forced them to frequently engage in a set of mental procedures, including; a continual vigilance of bodily movements and the continual anticipation of and preparation for potentially painful stimuli. Thus, the desire to avoid ILBP became an internal and permanent struggle in the minds of each participant during times of TLBP. Even though it was not possible to be permanently conscious of and forever thinking ways to avoid a recurrence of ILBP, this is something participants continually pursued. Therefore, the following two sections will outline how participants attempted to be permanently

conscious of ways to avoid a recurrence of ILBP, as they were continually vigilant of bodily movements and the continually anticipating and preparing for perceived painful stimuli.

A conscious vigilance of bodily movements

All participants were continually aware of how they moved to ensure no movement or posture compromised the comfort of their lower backs. Therefore, they were consciously vigilant and selective of their bodily movements/postures to ensure that they were continually avoiding the onset of ILBP. Participants were committed to this postural and bodily awareness for as long as CLBP persisted in their lives. Since all participants suffered from CLBP for an extended period of time (average 21 years), this acute awareness was a long term commitment, as Edna explained:

> *"So it's chronic, its just always there, it's always there, so if you move a certain way, you feel it more than – ya know, if your just resting or your just relaxing, so you always have to be making sure you move a certain way...to avoid the pain (5; 7; 5)."*

Steven had become so committed to his postural vigilance that it made him feel normal:

> *"I found myself being very fidgety...just constantly self adjusting my body to make myself feel normal (4; 10; 10)."*

Some participants provided specific examples of how they physically manifested a conscious vigilance of bodily movements in their everyday lives. Maureen explained how she was always altering her body positions to increase comfort and decrease the possibility of pain:

> *"I find a lot of my pain is um – the sitting – if I'm not um...like right now I'm not sitting properly but umm...if I am sitting at my desk working...putting my legs up so my back's straight, that feels better. I'm always altering my posture or position like that to help me feel more comfortable (3; 1; 37)."*

Brittany portrayed similar behavior when attending school:

> *"I couldn't sit still. I would have to move my hips a certain way or swing my leg over this way. It would be really hard for me to sit for an hour straight without being able to walk around while trying not to think about it (9; 5; 17)."*

Jacob vigilantly moved in ways he was sure would not compromise his lower back, as he was fully aware of what movements were likely to cause a recurrence of ILBP:

> *"Just making sure that I don't plant and turn. Even for simple little things you know. They happen so quickly, like you're rushing to do something – so it's always ugh...making sure my feet are moving, making sure I bend my knees and not my waist and picking things up - even the newspaper in the morning. (Gets up and demonstrates the proper way to bend) (10; 4; 42)."*

Evidently, the continual vigilance of bodily movements/postures led to frequent changes of bodily positions. However, continually altering bodily positions/postures to increase comfort or decrease/avoid pain required considerable thought and attention. For example, Michelle continually reminded herself of the different postures needed to avoid pain and increase comfort when attending a film at a movie theatre:

> *"I'm actually thinking in my head: 'Ok I need to just sit up straight, I need to make sure I have a good position, not too close, not too far back' And this all goes through my mind (1; 9; 30)..."*

In another example, Monique mentally surveyed a series of options for avoiding pain/increasing comfort before she engaged in any of them:

> *"I...I just think of – like right now I'm sitting here talking to you – I can feel the pain right here (points to low back) I'm thinking: 'Ok am I gonna cross my leg over and stretch this right now? Am I gonna dig my thumb into it? Am I gonna...ya know. I'm always altering what I'm doing to decrease the pain that I'm feeling. I'm always conscious of it (2; 6; 13).'"*

Experiencing ILBP forced Keith to constantly appraise how every one of his

movements would impact his lower back; something he never conceived was a possibility prior to experiencing ILBP:

> *"...you can't go through your day – at least so I thought, but I didn't think you could go through your day constantly thinking about your back and how every move you could make, could ultimately injure or re-injure your problem. But that's how it is for me cause I don't want to re-experience that pain again (referring to intense LBP) (11; 2; 24)."*

Although participants were consciously vigilant and selective of their bodily movements/postures to avoid ILBP, there were some cases where external factors also contributed to such careful and cautious behavior. Joanne found herself being extremely cautious after retuning to work from sick leave following a recurrence of ILBP:

> *"I got back on my feet, I had to get back to work, I had a job that I felt obligated to be there but after that, I watched it very carefully, was really aware of what I was doing and why I was doing it (6; 7; 18)."*

Gary explained how feelings of cautiousness increased following periods of ILBP:

> *"each time (after a pain flare up)...it got less normal because I had to think twice about: How do I sit? How do I get up? Do I bend over to pick that up? Do I squat? And you just sort of had to be very careful (7; 3; 16)..."*

For Marissa, it was the uncertainty of pain that increased her vigilance of bodily movements:

> *"it (LBP) would come and go, you would never know when it would strike, you could do something just as simple as bend over the wrong way, pick something up. It was a case where you had to stop and think before you made any kind of movements (8; 2; 25)."*

Although these external factors may have further influenced the conscious vigilance of bodily movements/postures, it was inevitably a desire to avoid ILBP that motivated this behavior.

<u>The continual anticipation of and preparation for perceived painful stimuli</u>

In their attempts to avoid the onset of ILBP, all participants tried to be continually aware of anything they perceived would be a potential source of ILBP. As a result, all participants would persistently anticipate potential sources of ILBP and subsequently plan or prepare strategies for avoiding them. Marissa felt that she was one slip or fall away from another recurrence of ILBP and this caused her to constantly anticipate barriers to stability and balance, such as weather conditions and footwear:

> *"I'm always thinking of: 'ok, what are the weather conditions outside? What kind of shoes should I wear for the least chance of slipping or falling (8; 6; 24)?'"*

Keith worked as a grocery store manager and the process of unloading stock off of a skid was a potentially dangerous activity he anticipated could initiate a recurrence of ILBP. He prepared for this potential source of ILBP by establishing a routine of safety:

> *"I mean I always have to remember to put my brace on if I am going to be lifting, I need to make sure there is a ladder there so I'm not sort of stretching and twisting right, and I need a kid to help me. So it's not like I can just go tackle any skid...I need to plan ahead (11; 3; 23)."*

Maureen advocated a different strategy than Maureen and Keith, as she felt the best way to prepare for an anticipated source of ILBP was through pure avoidance:

> *"I would hesitate doing things, John would say: 'Hey I need help moving that desk.' It would take me ten minutes to assess the situation before I say: 'no I can't do it.' Cause I know if I do it I'm gonna feel sore later and I don't want to feel sore later, so you're gonna have to find someone else to do it (3; 11; 3)."*

Some participants anticipated all potential sources of ILBP for the entire day and subsequently prepared strategies for avoiding them. For example, Joanne described how she would only plan to accomplish what she perceived she was capable of doing

without inciting ILBP:

> *"What I use to think was: 'what is it that I need to accomplish today?' In a sense that I need to get the windows washed, I wanna get the floor vacuumed. What can I accomplish today? What am I capable of doing today, without aggravating this, or without this becoming so intense that it's gonna lay me flat on my back for 2 days. So I would think about what I could do physically, in order to, kinda plan, how I was gonna deal with this pain or not deal with this pain or make sure I didn't intensify the pain, its like: 'ok, I think I can handle this today (6; 6; 28).'"*

Brittany explained how the intensity of her TLBP upon waking dictated the nature of activities she would plan for the entire day:

> *"Some days I could get right out of bed and do my things, other days it would be really slow to get out of bed... then I would just start thinking about, do I have a game today? If I do, will the pain go away by the time I gotta suit up or is it gonna be there like it usually is all the time? If I'm feeling good, then maybe I can do this or that. If I'm not then I should take it easy and see if I can feel better for the game (9; 4; 16)."*

Similarly, prior to starting his day, Jacob would plan many specific details that would help him get through all sources potential sources of ILBP:

> *"No I suppose I am thinking about how I am going to get through the day and planning, even from meeting – how am I gonna get from one meeting to another. What the train is like? Can I avoid steps? Things of that nature. I know I can't take the day off and lay in bed, things have to happen. But the approach for how I am going to do it and just a lot of grimacing (10; 5; 35)."*

For these participants, their perceived susceptibility to increased pain for the entire day was predicated on the intensity of their TLBP prior to engaging in any activity. Both participants would then use this perceived susceptibility as a framework for planning and organizing their daily activities, so as to avoid potential sources of increased TLBP and the onset of ILBP.

Some participants perceived that increased TLBP would enhance the possibility of a recurrence of ILBP. Therefore, these participants tried to continually

anticipate and prepare for sources of increased TLBP, so as to avoid a recurrence of ILBP. For some participants, this demanded much focus and attention. For example Edna explained:

> *"but now I'm really cognizant of things that can hurt my low back cause I don't ever want this to come back, so I spend a lot of time thinking about ya know, the different things that can hurt me or cause a relapse because part of the rehab is being aware of these things (5; 9; 26)."*

Steven also admitted to spending an inordinate amount of time thinking about potential sources of increased TLBP:

> *"first year of University, that was really the transition point where I was really thinking about it and I couldn't stop thinking about it. Like I would always be thinking about my low back and anything or anyway I could hurt it, just to help avoid pain (4; 8; 33)."*

Michelle compared her constant attention and awareness for avoiding increased TLBP to that of an overly protective mother's enthusiasm for ensuring the well being of her child:

> *"I guess like, its like, if you have a child or something, you just wanna make sure you always take care of it... It's like, its special (the lower back), it needs to stay healthy and if I'm doing anything throughout the day where it could affect my back, which could be a ton of things, I'll think about it (1; 9; 39)."*

Some participants provided specific examples of how they would mentally prepare for anticipated sources of increased TLBP. For example, Monique described her mindset when selecting footwear before going to work:

> *"Do I wear boots today? Do I wanna wear high boots? Because if I wear high boots two days in a row, then I can't have a third day because it's too much. Um...am I gonna put my running shoes on as soon as I go to school? Um...depending on how I feel that morning. "It's gonna wreck my outfit you know...if I wear my running shoes (2; 6; 25)."*

Monique's indecisiveness demonstrated just how difficult preparing strategies to avoid anticipated sources of increased TLBP can be; even if the potential source of

pain is fashionable footwear. However, this is not always the case, as Gary demonstrated in his explanation of preparing to eat at a restaurant:

> *"you anticipate where you're going, how many chairs do they have? If they don't have a chair that is comfortable, you have to bring stuff with you or you just stand or whatever so (7; 4; 32)..."*

Although Gary was also preparing for an anticipated source of increased TLBP (uncomfortable chairs), his strategy was more concise and simple.

Summary

It is evident that participants in this study continually thought about their lower backs and any potential sources of ILBP. Clearly, participants were committed to ILBP avoidance as they consistently engaged in a series of mental procedures to avoid the onset of a recurrence of ILBP. Their continual vigilance of bodily movements and continual anticipation of and preparation for potentially painful stimuli fundamentally altered the conscious thought and behavior of each participant. However, being constantly aware of the lower back and any perceived sources of ILBP was difficult for the participants, which is evidenced by their multiple recurrences of ILBP. Therefore, the desire to establish a permanent pain consciousness was never fully achieved by the participants. Being conscious of all sources of ILBP and consciously moving in a vigilant manner to always avoid the onset of ILBP are nearly impossible feats. To be at such a conscious level of awareness requires a lifetime of deconstructing and reconstructing instinctual movement and thought patterns and as Jacob explains, this is something no one can likely ever achieve:

> *"Umm...I think if you do it enough it starts to become 2nd nature, there are times though that, you don't know what happened it's – I don't think you can*

> *hardwire it, you wish you could, but I've always heard that in anything – in any sport, in teaching people a skill, the toughest part is getting them to unlearn their bad habits, because in times of stress, that's what's imbedded the deepest and that's what comes back, how to do it improperly. And ugh...so I suspect that's what's happening, you're busy and something else is taking over and a bad habit kicks in (10; 6; 37)."*

Each participant's multiple recurrences of ILBP supported Jacob's assertion that people will disengage at times and rely on those "bad habits" which can incite ILBP. The desire to establish a permanent pain consciousness characterized by the continual vigilance of bodily movements and the continual anticipation of and preparation for perceived painful stimuli, showcased each participants desire for avoiding any further recurrences of ILBP.

**Theme # 2 – Personal susceptibility to pain**

As discussed in the previous theme, participants were consciously vigilant of bodily movements and continually anticipating and preparing for potentially painful stimuli to avoid a recurrence of ILBP. All participants felt extremely susceptible to experience a recurrence of ILBP following the recovery of their initial bout with such pain. Furthermore, each recurrence of ILBP reinforced each participant's perceived susceptibility to experience another. Therefore, their desire to avoid a recurrence of ILBP was based on their perceived susceptibility to experience another. It is clear that each participant's perceived susceptibility to experience a recurrence of ILBP directly impacted the vigilant behavior they exhibited in their pursuit of a permanent pain consciousness. For example Brittany felt her personal susceptibility to pain forced her to be cautious and vigilant at a very young age:

> *"I would always just judge how bad it was and if it was hurting just a little bit I would be more apt to go and do whatever and hang out but if it was really bad I would just stay home and miss out on these life experiences, when I'm*

*like 15 years old. And I had to be that way because if I wasn't careful or cautious with it then I could really hurt it (9; 5; 35)."*

Monique's susceptibility to pain forced her to be constantly aware of how she moved:

*"you know, it's just, everywhere (LBP), so I have to be constantly aware of what I'm doing and how I'm doing it (2; 8; 1)."*

Maureen explained how she was highly likely to experience a recurrence of ILBP if she did not focus on her lower back:

*"I thought about it twenty four, seven. I mean I am always thinking about it because I have to because if I don't then I will forget and I'll end up hurting myself (3; 8; 25)."*

The same can be said for Keith's, as he felt highly susceptible to a recurrence, particularly when at work:

*"And I have to be like this because if I'm not than I'll be more susceptible to having severe pain I guess or at least initiating the pain that we've pinned down as the moderate one (11; 3; 32)."*

Edna felt trapped by her commitment to focusing on her lower back and vigilant behavior:

*"It's almost like I'm trapped like a prisoner. Your restricted, you know, your mind is always focused on your low back because there are consequences for your actions...if you do something your not suppose to (5; 14; 21)."*

In some cases, participants felt susceptible to ILBP from the most mundane movements/actions, as Gary explained:

*"because just moving the wrong way, you can get a real sharp pain that causes everything to freeze up (7; 8; 40)."*

and Marissa reiterated:

*"you turn the wrong way - bang - it could go out (8; 12; 31)."*

Joanne provided a specific example of such susceptibility:

> *"lifting a heavy bag or lifting the kids or whatever, would make it (the low back) inflame... so I had to be careful (6; 4; 24)."*

In these cases, an increased susceptibility to experience ILBP forced participants to be consciously aware of how they moved.

Some participants felt their perceived susceptibility to ILBP forced them to consciously engage in bodily postures that would help avoid increased TLBP. For example, Michelle, tightening her mid section was crucial for avoiding increased TLBP:

> *"if I don't think about it, then I forget and then I let my stomach or my back relax and then something starts hurting (1; 10; 6)."*

In the case of Steven, his embarrassing body quirks were imperative for avoiding increased TLBP:

> *"I won't want to display those quirks that make it a bit better because I'm thinking about it and I don't want others to see that. But I feel like I have to or I automatically do because if I don't then I'll start to get low back pain (4; 12; 40)."*

Jacob went on to describe how increased TLBP often acted as a physical reminder to re-engage in his vigilant behavior:

> *"And when you do it (forget to be vigilant and hurt your back), you think: 'god that was stupid.' Its like: 'what was I thinking?' The answer was I was day dreaming or my mind was somewhere else and the body just did it. And my mode of watching how I do it didn't happen (10; 6; 26)."*

Summary

It is clear that each participant's perceived susceptibility to experience a recurrence inspired their desire to avoid ILBP and their pursuit of a permanent pain consciousness. However, each recurrence with ILBP reinforced this susceptibility. Since all participants felt that a recurrence of ILBP was probable, it is clear that

personal susceptibility to experience such pain persisted throughout their entire CLBP experience. However, as the sub theme "living with a weakness" will demonstrate, all participants perceived their lower backs to be a weakness which further perpetuated their perceived susceptibility to CLBP and long-term pain.

**Sub theme: Living with a weakness**

Each participant explained how they felt as if they were living with a weakness. This weakness was perceived to be the lower back itself; however, the participants expressed this weakness in three meaningful and unique ways.

Experiencing CLBP for a prolonged period of time convinced some participants that they always had a weak lower back. This was the case with Michelle:

> *"I always felt like I had just a weaker back muscle or area (1; 3; 7)"*

and Edna:

> *"Oh yes...yes. Yah...well as long as I can remember I've always had a weak low back (5; 3; 23)."*

Furthermore, both Joanne and Marissa felt this weakness would continue to cause them grief, as it was a part of their life:

> *"So it is, I guess a weakness; you would have to call it. Its there, it's always been there; it's never going to go away (6; 3; 35); "So I've always had this weakness that has affected my whole life and I can't just get over it because it's always there (9; 7; 5)."*

Keith felt his weakness was the reason why he would experience TLBP in situations when most "normal" people would not:

> *"I always feel like that portion of my back is weak, um...and it gets sensitive quickly, I am not going to say every single day I have pain but, you know...even if I sit in a pew at church for a long period of time or if I'm at my daughters recital or if I am sitting in an uncomfortable chair for a long period of time, it will start to flare up again and it will hurt and I know that's not normal (11; 2; 31)."*

Finally, Jacob equated his CLBP struggles to a never-ending battle with an internal weakness:

> *"So this has been a weakness in a sense for me. Something I've had to overcome all of these years and will continue to battle with – for as long as it takes – forever I suppose (10; 12; 40)."*

These participants were living with a weakness they perceived made them susceptible to CLBP and would continue to do so for the rest of their lives.

Some participants actually explained how living with a weakness correlated with increased TLBP. These participants thought their lower backs were a medium the body used to express added stress they were experiencing in their lives. Therefore, the lower back was the "weak spot" of the body that would express encountered stress through increased TLBP. Maureen articulated this idea rather concisely when explaining how increased stress levels from work would lead to increased TLBP:

> *"yah I'd feel the pain periodically but when a lot of pressure and stuff came onto my shoulder, I felt stress and I started experiencing a lot of low back pain...It's almost like all your pain; everything goes to that one weak spot. So I felt like I was carrying a lot of stress and my stress was being carried in my back and I started experiencing back pain again (3; 10; 26)."*

Gary was an elementary school teacher who would always experience increased TLBP during parent teacher interviews, as he found this to be a stressful day:

> *"yah I will have lower back pain, but not acute lower back pain. Like walked stopped over and ugh....then when the event causing the stress or anxiety passes, I'm fine, so that's when I figure: 'oh there's some psycho somatic control over that too (7; 8; 20).'"*

Interestingly, the increased intensity of his TLBP would subside when stress levels decreased. Steven discussed how beginning his first year of University was very stressful and provided an explanation for how this increased TLBP:

> *"Yah. I think it was more just myself putting extra mental stress on my body which in turn made the dull low back pain into a more searing back pain that I – that I felt like I could not handle at the time (4; 7; 28)."*

The remaining three participants felt that eliminating their weakness would alleviate their pain and suffering. However, they all desired to remove the weakness by physically dissecting the injured/damaged body parts from their otherwise healthy bodies. This was illustrated by Monique who felt she was carrying a weak low back around with her:

> *"It felt like my low back wanted to be cut off... so as to stop the pain...if that makes any sense...the low back pain....it was like I had to carry my back around with me and that was causing me pain (2; 3; 41)."*

Likewise, Marissa felt dissecting her body would end her suffering:

> *"If I could cut myself off between the neck and the torso, it would be fine. I wouldn't have to deal with that situation (8; 6; 30)."*

Brittany also expressed a desire to "cut out" her weak low back:

> *"Even if my (baseball) stats proved otherwise, it just made me feel weaker because I couldn't push myself as much as the other girls were. I know this sounds silly but sometimes I imagined cutting out my low back so I could get rid of the weakness because it was the reason I just couldn't physically play my best. So it made me feel like I was less skilled than other people too (9; 7; 9)."*

These three participants all had unrealistic desires to remove or "cut out" their lower back's from the rest of their bodies, as they felt removing the weak spot would eliminate their pain and suffering.

Summary

Clearly, these participants all felt that they were living with a weakness. This weakness was perceived to be the lower back itself, as all participants felt that a "weak low back" directly contributed to their CLBP. Some participants felt this

weakness inherently predisposed them to CLBP. Others felt their lower back's operated as a mechanism for expressing all forms of stress, thus increasing their susceptibility to increased TLBP. Finally, some participants felt physically eliminating the "weak spot" would end their pain and suffering.

All participants felt susceptible to increased TLBP, a recurrence of ILBP and long-term CLBP. This susceptibility was established and reinforced by recurring episodes of ILBP and further perpetrated by the perception that they were living with a weakness and thus, inclined to suffer. Living with this susceptibility created a desire to avoid ILBP that obligated participants to vehemently pursue a permanent pain consciousness (as documented in theme 1). However, as theme 4: "Lived fear based on the perceived consequences of anticipated ILBP" will explicate later in this analysis, personal susceptibility was instrumental in the development of each participant's fear of pain.

**Theme # 3 – Depression based on feelings of helplessness**

All participants discussed how periods of ILBP were extremely discouraging and depressing. This depression was directly related to feelings of helplessness. Physically, participants felt helpless as the effects of ILBP were incapacitating, immobilizing and debilitating. However, participants suffered through ILBP with an uncertainty for how long the pain would persist. Therefore, both the loss of physical functioning and the uncertainty of pain duration during bouts of ILBP combined to create feelings of helplessness, which ultimately produced a depressing experience.

Steven illustrated this idea rather well when he explained why physical ILBP was so depressing for him:

> *"Because I wouldn't know how long it would last and I'd be stuck in my bed or on the couch watching TV cause it hurt to move. So those were always the most depressing times (4; 8; 24)."*

Maureen was unaware of what to expect during bouts of ILBP, as she felt no one could help her:

> *"When it came to a ten, I was in tears, I was depressed. I was um...very hard to deal with, because there was this pain that no one could help me with and I didn't know what was next (3; 8; 33)."*

Michelle expressed similar feelings in her recollection of experiences with ILBP:

> *"Like calling my mom and being upset on the phone: 'I'm so tired and always annoyed and I'm upset like...and my back hurts all the time and it's always there...when will it go away?' And that was a problem because a lot of the time I couldn't even move (1; 8; 40)."*

Many participants' experiences with ILBP were so painful they could only manage to lie supine, while helplessly contemplating how long the pain would persist. For Brittany, this experience brought her to tears:

> *"I remember lying on my floor at home and my mom just touching my back trying to massage the pain out and I was in tears and I remember thinking: "when will this go away (9; 2; 26)?"*

This was also the case for Joanne who experienced true despair during periods of helplessness:

> *"Oh I have. In times of really severe pain when I am on my back pretty much...there have been times when I've balled my eyes out because its like: 'how long is this gonna go on, when is this gonna stop, when am I gonna get relief (6; 12; 42)?'"*

Marissa only recalled feeling depressed during periods of ILBP. This was due to incapacitating pain and the uncertainty of her immediate future:

> *"Only when I was flat on my back. I would get very depressed. It was like, when is this going to end? Am I gonna start getting better? Will I feel better tomorrow? When will the meds kick in? Kind of thing (8; 9; 9)."*

Similar experiences made Edna feel much like a cripple and significantly depressed:

> *"(Why were you depressed?) Because I couldn't do anything, I was lying on the couch. I had to physically get on my knees and dragging myself to the bathroom – terrible. And I didn't know what was next. I thought: 'this is it for me.' I felt crippled, and I said: 'oh my god, I can't even get my kids their clothes or pick up (5; 14; 29)... '"*

Monique and Gary suffered from unique uncertainties that intensified their feelings of helplessness. For Monique the unpredictability of ILBP coalesced with the physical debilitating effects of such pain and the uncertainty in which it persisted to create a truly helpless and depressing experience:

> *"And it can always get worse and that's the thing I keep discovering, at any time I can be laid up on my back again thinking: "ok now how long is this one gonna last" and that gets depressing so (2; 10; 35)..."*

Gary expressed an uncertainty for whether he would ever regain proper mobility. This combined with his uncertainty of pain duration and a loss of mobility to create a helpless and depressing experience:

> *"When it's chronic. You think how many days is this gonna be? Is this gonna months? Will I ever be able to walk straight up again? That loss of mobility. And the despair in thinking: 'oh is this ever going to go away, will I ever be back to normal (7; 12; 45)?'"*

Keith was always uncertain of what to expect during periods of ILBP:

> *"Yah well I mean depending on how badly I'm injured, I mean, the recovery never seems to be exactly the same, so you never know. What if I seriously damage myself this time? What if it doesn't heal? How long am I gonna be held up for (11; 4; 15)?"*

However it was Keith's physical inadequacy and inability to help others during this time that was truly depressing:

> *"And....maybe – I don't know the feeling off being inadequate or not being able to contribute plays on your mind from time to time and that is the most depressing part for me – particularly when I am held up on the coach or in bed and not doing anything because I'm helpless (11; 5; 18)."*

It seemed the consequences of physical helplessness negatively impacted Keith's own perceived self worth, which was depressing.

In a unique case, Jacob had experienced so many recurrences with ILBP that he eventually began to establish a sense of certainty in which such pain would persist and eventually subside (usually four to six weeks). However, this was only temporary, as he later succumbed to a series of recurrences characterized by uncertainty of pain duration. His description of his first experience with ILBP demonstrates a response akin to that described thus far:

> *"When the six weeks came around and it wasn't better, that's when a different mind set... in, like: "what have I now done?" And is it deteriorating as a whole? Where are we and what's happening? And this was probably one of the most depressing times for me. I think if people knew where the end was, they would gut their way through and do what they had to do to get there but not knowing, uh....in life, its a lot of things. Not knowing is the real killer on our minds and in our approach to things (10; 13; 5)."*

Summary

All participants suffered from depression during times of ILBP. This depression was based on feelings of helplessness, which in turn were based on physical immobility and an uncertainty for how long ILBP would persist. Physical immobility would force participants to suffer through agonizing pain, typically in a lying position. During this time participants would question and ponder the uncertainty for how long such pain would persist, as all participants felt susceptible to progressive agony during times of ILBP. Therefore, physical helplessness resulting from debilitating pain and the uncertainty in which it persisted combined to create the quintessential depressing experience for each of the participants. The more recurrences of ILBP a participant endured, the more depressing their experiences

were.

**Theme # 4 – Increased frustration based on an inability to receive medical help/ support**

No participants were able to establish a successful routine for managing ILBP within the medical community, which often lead to increased feelings of frustration and disdain for the medical system. Individual accounts of such frustration are documented below and in all cases, the uncertainty of pain, unrealistic pain expectations, and the uncontrollability of pain influenced each participant's negative appraisal of health care. Participants expressed these frustrations through a perceived lack of support and through reports of ineffective communication and a lack of understanding between the patient and the health care professional.

Given the uncertainty of pain during times of ILBP participants were never really sure what to expect. Uncertainty would have been even greater during each participant's first bout with ILBP, as this would have been a completely unique pain that each participant had no previous experience with at all. Given the physical helplessness and lack of control during this time, participants would often consult health care professionals for help. Participants expected these professionals to help reduce pain they felt incapable of managing alone. However, it seemed that physicians advocated a belief in "the power of the body to heal itself" as they typically offered no way for decreasing the debilitating pain aside from bed rest and the use of pain medication. Michelle, Steven, Brittany, Maureen, Joanne, Keith, and Jacob expected more from their physicians and became frustrated with inadequate support on behalf of the people they expected to help relieve their pain.

Michelle experienced two episodes of ILBP which she completely recovered from; pain free. These episodes were somewhat similar as they each persisted for approximately two weeks and she responded with a full recovery both times. During both episodes, Michelle recovered with bed rest and pain medication use. However, she suffered another recurrence as a result of a herniated disc. This bout of ILBP persisted longer than previous occurrences, was the most painful of all three and gradually decreased into TLBP that has persisted ever since. In a sense, this latest bout of ILBP could be recognized as her initiation into the CLBP experience. Following this latest recurrence she consulted her general practitioner. However, her general practitioner suggested the same treatment modalities Michelle used to recover from her previous two occurrences (rest and pain medication), as he had no way of determining what was wrong. This truly frustrated Michelle:

> *"So I didn't get any diagnosis. I also – that was also something that was frustrating, was not knowing what was wrong. Like I didn't know what I did to myself, I wasn't – and I didn't really blame that on anybody but I wasn't really told what was wrong and I didn't understand completely why I was experiencing this or what I could do to help myself besides taking drugs or whatever – medicine. So that was also frustrating (1; 5; 24)."*

Clearly Michelle had unmet expectations during this consultation.

In the case of Steven, he consulted different chiropractors following his initial episode and only recurrence of ILBP, at a time when the pain was still persistent but slightly less significant. He discovered that these chiropractors would all have an answer or diagnosis for what was causing the pain but they were not able to curtail his pain and this frustrated Steven:

> *"Well it pissed me off because you have to remember this chiro that I like is the last one I saw, so when I first went to seek some help from these other guys it was so discouraging because they couldn't really help me. Sure they could*

> *diagnosis it and that but then they would just keep brining me back and I wasn't moving forward (4; 6; 27)."*

Brittany was extremely frustrated with her initial consultation following the onset of her original experience with ILBP. However, she originally engaged a physiotherapist:

> *"So, in the beginning that's what frustrated me because the physio people didn't know what they were doing. They didn't help the problem but if you go to someone who knows what they're doing, you can fix the problem (9; 6; 26)."*

The inability of health care professionals to meet Brittany's expectations for immediate pain relief created a frustrating experience for her. Michelle, Steven and Brittany were all in the 20-30 age range and had experienced CLBP for an average duration of five years. Therefore, they had only experienced two to thee major episodes of ILBP each. Michelle experienced three, but it was not until her third occurrence that she conceived ILBP to be a real problem and consulted a physician. Therefore, each of these participant's experiences with medical treatment during times of ILBP were disappointing and frustrating.

Maureen was a unique case in that she experienced the gradual onset of TLBP without significant injury. Living with TLBP was manageable until a chiropractor further injured her back:

> *"and I started seeing another chiropractor because I couldn't see Joe all the time. And apparently this chiropractor who always just, crunch, crunch, crunch, crunch (making crunch motions with fists). He just crunched one too many and now I have been told by another chiropractor, that I have degenerated disc disease and issues with the sacrum (3; 1; 33)."*

This was her first experience with ILBP. Maureen later experienced a much more devastating recurrence of ILBP, which persisted for two months. When this pain

gradually began to subside, but still lingered as a problem of somewhat lesser severity, she engaged a chiropractor to help with pain relief. During this time, she expressed adamant frustrations with the inability of her chiropractor to provide substantial benefits:

> *"I- Right and so, after seeing that doctor, you stopped seeing him because? P- It starting costing and we weren't progressing; he could only help relieve the pain temporarily. I didn't have the money to keep paying up, so I became really frustrated (3; 6; 33)."*

Maureen's experiences with chiropractors were truly frustrating for her.

Joanne's very first experience with ILBP was very frustrating. She felt her initial pain was much more serious than her general practitioner may have thought. She was irritated with the lackadaisical attitude in which he approached their consultation:

> *"(imitating physician) oh yah, you know, you've injured your back, can you bend forward? Can you bend this way? Can you bend that way? Can you lift your legs? Can you, you know, they go through their usual routine of lets see what your mobility is and where's the pain. And um...yah well it's gonna take some time and your just gonna need some bed rest. So they advised bed rest and some pain killers, which was really frustrating to me (6; 1; 42).'"*

It seems Joanne was frustrated by her physician's flimsy assessment and the prescribed treatment modalities, all of which she attributed to a sense of carelessness on behalf of the practitioner. Joanne went on to experience two other major recurrences of ILBP, the first of which she was barely able to manage without medical intervention (during trip to England) and the second of which she tried acupuncture in the hope of some immediate relief. However, this latter experience with acupuncture was perhaps the most frustrating of all:

> *"I haven't got 2 hours to sit there but also he tried acupuncture and it was making me worse. It wasn't that it wasn't helping, it was making me worse. I came out of there one day, I was screaming at the top of my lungs (6; 7; 35)."*

Keith experienced four major occurrences of ILBP. Following his original experience, he consulted a chiropractor but expressed a similar frustration to that of Steven:

> *"When I first hurt my back I wasn't sure what to do. I finally decided to go see a chiropractor and what I found out was that my pelvic bone had shifted and this was causing pain with my sciatic nerve, which explained why I was getting the pain in the leg I guess. And the reason I say "I guess" is because he wasn't able to do much for me other than diagnosing the problem and that was aggravating for me and my back...(11; 1; 34)."*

It seems these chiropractors were capable of diagnosing each participant's pain but unable to provide substantial pain relief; which truly frustrated Steven and Keith. Keith's next two recurrences were similarly frustrating for Keith, but with different chiropractors. It was not until Keith's third recurrence that he was able to find a chiropractor that could help him with relieving his ILBP.

Jacob's only disdain or frustration towards the medical system was during his very first consultation with a sports medicine physician immediately following his initial injury:

> *"...they said (doctors at sports clinic) it was just a tweak and it was going to be fine, if it was something really bad they were going to send me to the hospital, they didn't so, it was going to be fine. So I think it was firm belief in the power of the body to heal itself. Which was frustrating, because this wouldn't be the case (10; 7; 28)."*

In a unique and rare case, Jacob actually managed to temporarily establish a pattern of certainty during times of ILBP. He would experience a recurrence every two to five years and they would persist for four to six weeks with or without medical intervention. This made his experiences with ILBP less frustrating than the rest of the

participants. However, his most recent occurrence persisted for ten months and thus, the uncertainty of pain re-emerged.

Each of these participants was clearly frustrated with a lack of medical support throughout their experiences of ILBP. For all participants these frustrations were prominent following their initial engagements with health care professionals following their first experience of ILBP. For those that experienced recurring episodes of pain, they were all (except Jacob) unable to establish a successful routine within the medical community for managing their pain and this was at times equally frustrating.

Although a perceived lack of support frustrated most participants during their initial engagements with the medical community, this was not the case for Edna, Marissa, and Monique. These participants expressed a frustration with the medical community when they were forced to rely on medical intervention in order to heal their ILBP. In each case this was based on the inability of health care professionals to communicate with and understand their needs.

During Edna's first two bouts of ILBP (she experienced three) she managed her ILBP with bed rest and minimal pain medication (small doses of anti inflammatory), as she refused to engage in any consistent treatment modalities. However, when she needed to have surgery to repair two herniated discs, the support she required was not there for her. Following the injury and leading up to surgery Edna had been suffering from ILBP and her doctor had prescribed a number of narcotics to help her manage the pain. Taking these drugs contributed to a depressing and discouraging experience, which increased Edna's frustration with her doctor:

> *"This is crazy I've never been on narcotics until Nov 12th or 13 2008. I'm taking myself off them, this is nuts." I went to see Dr. Hill Dec 23rd, 2008 and I said: "no, this is it." Who puts someone with no history of pain killer use on 9 narcotics!? She explained all the narcotics to me and I took myself off every single one of them (5; 15; 23)."*

Prescribing multiple addictive narcotics to a patient with little to no history of prescription drug use exemplifies the lack of communication and understanding between Edna and her doctor that was truly frustrating.

Marissa experienced three episodes of ILBP. Much like Edna, she managed her first occurrence through bed rest and pain medication, as her general practitioner had prescribed. However, her following two recurrences were treated with surgery. Treating the same problem with two separate surgeries was frustrating enough for Marissa, however her true angst for the medical system was based on the lack of communication during the second surgical procedure:

> *"I wasn't happy with it. The fact I had to change the meds myself. And here you're trying to deal with a pick line right in your back and have a pouch with the antibiotics right here. There's no communication in the medical system in that and it can be so frustrating (8; 10; 13)."*

Marissa was a retired nurse and later went on to explain how the lack of communication between doctor and patient could partially be accredited to the poor structure of health care and health care facilities:

> *"You need someone in your corner to help you. See in the medical system, you use to get back ups, visiting nurses and that kind of stuff, unless the doctor specifically requested because I went to a surgeon outside the city of st kitts. They are not as co-operative with the dr's here in the city (9; 9; 45)."*

She even recommended ways to improve communication and treatment of CLBP:

> *"If there were some way, like you could go in for a test every 6 months or something to get your back tested that would be perfect. So someone better come up with something. I just wish we had more doctors and better facilities" (8; 14; 17)."*

Monique sustained a traumatic injury as a result of a workplace accident. Much like the previous two participants she exhibited a willingness to "wait out the pain" during her initial experience with ILBP. However, following her second occurrence she needed to take time off work to heal and thus, was forced to rely on the medical system to help facilitate the process. The Work and Safety Insurance Board (WSIB) obligated her to engage a neurologist. This neurologist was to determine a list of exercises for Monique to adhere to during physiotherapy treatments during her time off work. However, once again, a lack of communication and understanding created a frustrating experience for the participant. It was the neurologist's tendency to impose her own ideals, while ignoring the participant's athletic disposition that truly frustrated Monique, as this has restricted her access to resources of pain management:

> *"The thing that I find frustrating, is that...umm, so much was placed on the neurologists findings and she was very conservative with what I couldn't do and her ruling was of the top priority, so my physiotherapist wouldn't do certain treatments because of her recommendations but there must be other neurologists who maybe have more of an athletic view of things. So I feel unlucky, in one way with who I had because I don't know if I got the full treatment of what I can and cannot do (2; 14; 13)."*

In this case, a lack of communication between patient and health care professional directly impacted the patient's ability to heal and find the support she required. This was truly frustrating for Monique.

Although Gary was not forced to rely on medical intervention to relieve ILBP, he engaged different health care professionals following each of his three major occurrences with ILBP. However, he was never able to establish a successful routine

for managing such pain, which he also attributed to a lack of communication between the doctor and patient:

> *"They're not gonna listen to all the – how did this happen and what's wrong. They'll send you for x-rays, they'll look at them and say oh this is it – take this. And if there's anymore problems give me a call and we'll make another appointment and that's it. They don't wanna listen; they don't give you the time. I- How does that make you feel? P- I feel resentful (7; 10; 37)."*

Summary

Clearly each participant became extremely frustrated with the medical community during times of ILBP. Individual accounts of participant frustration based on a lack of support and a lack of communication following both initial and recurring experiences with ILBP demonstrate the magnitude and consistency of this problem throughout the CLBP experience. However, there are certain underlying factors which inherently presupposed participants to frustration during medical engagements following recurrences of ILBP.

The first was uncertainty of pain. Part of the reason participants could not establish a pattern for treating and recovering from a period of ILBP was due to the uncertainty of such pain. As previously alluded to in an earlier section, the onset of ILBP was always unexpected, the duration in which it would persist was unknown, the intensity of pain was consistently high but the thought of progressive agony was always a concern, and the time in-between pain episodes was variable. Therefore, participants could not develop clear pain patterns/expectations. Without clear pain patterns, managing, treating, and relieving such pain became exceedingly difficult. To further understand this, consider pain management during times of TLBP. The TLBP participants experienced everyday was similar in pain intensity, pain duration and in

the movements which increased/decreased pain. Participants were able to establish clear pain patterns/expectations based on this certainty. Identifying clear pain patterns/expectations afforded participants the opportunity to establish pain management strategies they could consistently rely on to decrease TLBP and/or prevent future occurrences of ILBP. Knowing exactly what type of pain to expect on a day-to-day basis provided participants with a consistent reference point to accurately evaluate the effectiveness of different pain management strategies. It was a matter of trial and error. If one modality did not work, they could try another (swimming vs. walking vs. biking etc). As one would expect, each participant developed an effective strategy for managing TLBP, some of which involved the help of a health care professional. However, these were all preventative measures that participants could not rely on during a bout with ILBP. Regardless, it is clear that the certainty in which TLBP existed directly influenced the possibility of managing such pain.

Although pain-related certainty seemed to influence each participant's appraisal of TLBP and ILBP, the different goals and expectations of participants during times of TLBP and ILBP was another significant influencing factor. First consider ILBP. Participants expected an immediate diagnosis and immediate pain relief. These were impractical goals and expectations given the uncertainty for which such ILBP persisted and the difficulty in accurately diagnosing low back ailments. Now consider patient expectations of the medical system during times of TLBP. During this time patients work on pain prevention, much of which they could do on their own. If and when they engaged health care professionals during this time, they

only expected them to help facilitate the process. Although preventing recurrences of ILBP over time by gradually adopting preventative lifestyle activities (e.g. exercise) may seem challenging or unrealistic, it was not for these participants. Each participant in this study was proactive and enthusiastic about adopting healthy lifestyle choices to help manage their TLBP and prevent a recurrence of ILBP. Therefore, it is clear that unrealistic expectations during times of ILBP influenced each participants frustration and disdain with the medical system during such pain. Furthermore, patient expectations of pain relief were more compatible with physician expectations of pain relief during TLBP. This was not the case during times of ILBP as physicians typically invested in "the power of the body to heal itself" and participants generally expected quicker results, which contributed to patient frustrations with medical management during this time.

The issue of controllability must also be addressed as this is another underlying factor that dictated each participant's negative appraisal of the medical system. Participants managing TLBP were working with a physician to help establish a routine for healthy living. This put participants in a position to control and manage their TLBP independently. During times of ILBP, participants had practically no involvement in decreasing pain intensity and had to rely completely on pain medication, a general practitioner, a neurologist, a surgeon etc to relieve their pain. Participants had to rely on health care professionals for help and when these people failed to support or understand them, frustration on behalf of the participant ensued.

**Theme # 5 – Lived fear based on the perceived consequences of anticipated ILBP**

All participants lived in fear of re-experiencing ILBP. This fear was based on

what they perceived the consequences of an anticipated recurrence with ILBP would be. This fear existed as long as there was potential for recurrence in the mind of the participants and as illustrated in theme 2, all participants felt susceptible to a recurrence of ILBP. Therefore, all participants lived in continual fear of suffering through the perceived consequences of an anticipated recurrence of ILBP.

The nature of these perceived consequences were inextricably linked to the idea of immobility and permanent restriction. For example, both Maureen and Steven were afraid that ILBP would one day inhibit their ability to walk:

> *"Not walking. I worry about not being able to walk one day (3; 11; 18)"; "...you find cases that are much worse and that's what I was scared of those people who couldn't walk or whatever because I didn't want that to be me...I don't want that to be me (4; 9; 22)."*

Marissa and Joanne reaffirmed this fear as they were both afraid of becoming wheelchair bound:

> *"And then there's the ultimate fear of ending up in a wheelchair someday. I think that would kill me more than anything else (8; 6; 31)"; "That's actually my biggest fear. Yah...I would be a very poor patient if I was to end up in a wheelchair where I can't handle myself, I can't do things for myself (6; 10; 26).*

Although the latter excerpt illustrated Joanne's fear of ending up in a wheelchair, it also represented her fear of losing independence and functionality; a concern she previously expressed in her interview:

> *"my fear is, not pain, my fear is not being able to function in my normal everyday – where I need to pick up my grandchildren, or yah know, go visit with friends, doing laundry, my housework (6; 9; 20)."*

Michelle reaffirmed this fear as she worried future experiences with ILBP would inhibit her ability to function normally:

> *"because I can twist my ankle again, that's not gonna bother me, that will only take a couple weeks. I don't ever want to hurt my back again because it takes so long to heal and I want to be able to live a normal life and be functional (1; 10; 21)."*

Clearly these participants' perceived that anticipated bouts of ILBP had the potential to permanently incapacitate them, as they lived in fear of losing the ability to function as mobile human beings.

The fear of being permanently incapacitated by ILBP created a foundation for additional fears. For example, Edna lived in fear of not being able to function as a parent. As a mother of two, she felt a recurrent bout of ILBP would make her incapable of supporting her children:

> *"it's the most painful – especially when you have acute sciatica, its unbelievable. So worry more about what I do and really being - better to myself so I can help my kids because I'm terrified and I worry about not being able to support or help my kids (5; 9; 31)."*

Although it has been established that Monique lived in fear of being bed ridden from ILBP, she also feared prolonged immobility would prevent her from supporting her children:

> *"I just wanna be healthy so I can take care of my kids. That's my goal. Get up go to work, yah know, not have to worry that I'm gonna have a month that I'm laid up like I had before (2; 5; 30)."*

In a unique case, Maureen feared ILBP would impede her ability to procreate:

> *"I don't know...I don't know. I haven't had a child so- does having a child – do I have that fear, sure. Like...do you carry a child for nine months – and here I'm getting emotional now – and then I can't (tears) (3; 11; 22)..."*

Keith lived in fear of not being able to support his wife and children due to potentially becoming incapacitated and losing his job as grocery store manager. The possibility of losing his job due to ILBP also played into his fear of being dependent

on others, especially his wife:

> *"I'm afraid that if I miss too many shifts or if I permanently injure my back then I can't support my wife or children and it's a little stressful to know that one day I may injure my back to the point where I cant work because that will put a huge burden on my wife's shoulders (11; 5; 14)."*

These fears were re-emphasized by Jacob:

> *"(What are you scared of?) The length of time. I don't mind – I can gut my way through another bout of pain. It's the duration of it and what that might impact work wise or family wise (10; 9; 16)."*

These participants seemed to worry that the incapacitating effects of anticipated ILBP would prevent them from supporting people they cared about.

In some cases, participants were fearful of both the method in which they anticipated ILBP would recur and the consequences they perceived such pain would have. For example, Brittany and Gary lived in fear of one day becoming paralyzed from ILBP via a major accident. Smith feared that one misplay in baseball would lead to paralysis:

> *"I thought worse case scenario that one day that I would...I would get hit and I would be paralyzed because it was my back and I knew enough that it was a pretty serious thing and that happens to people all the time (9; 5; 7)."*

Gary feared the possibility of a traffic accident and the likelihood of paralysis:

> *"Uhh...a traffic accident, because you know, you hear all these stories and that's all I need. Cause I already have a pre existing condition and whiplash or something like that is gonna really aggravate that. And just the scary thought of being paralyzed (7; 8; 3)."*

It was evident that both Brittany and Gary felt susceptible to re-injury and were afraid of one day becoming paralyzed via ILBP. However, they both anticipated a mechanism in which they perceived such pain and consequent paralysis would occur (e.g. misplay in baseball / car accident). Therefore, they subsequently lived in fear of

both the anticipated method of re-injury and the perceived consequence of ILBP. Similarly, Monique feared an auto crash, as she felt susceptible to ILBP from the slightest accident:

> *"I'm terrified of getting into a car accident because it could ruin everything, whereas a normal person might just get a bit of whiplash, I could be bed ridden again, from the smallest impact (2; 6; 45)."*

The only difference for Monique was that she was ultimately afraid of being bed ridden as oppose to paralyzed. However, this was a rather minute disparity considering both represent a fear for losing the ability to move, either temporary or permanently.

Summary

All participants were afraid of experiencing what they perceived the consequences of anticipated episodes of ILBP would be. These consequences were perceived because they were based on a potential experience of ILBP that had yet to occur. However, considering that the perceived consequences of anticipated ILBP were similar to consequences of previous episodes of ILBP, the formations of these perceptions seem to have been influenced by previous experiences. For example, a loss of mobility, an inability to function normally and an inability to support others are all major fears that participants had been exposed to during previous experiences with ILBP. However, their previous experiences with these consequences were only temporary (e.g. temporary loss of mobility, temporary loss of functionality, temporarily unable to support kids) as all participants were mobile and able to function capably and independently at the time of their interview. Meanwhile, the fears expressed by the participants during the interview were based on what they

perceived would be permanent consequences of anticipated ILBP (e.g. no longer able to walk, in a wheelchair, parlayed, no longer able to support kids) and thus, more devastating than any consequences of ILBP they had previously experienced. Some participants were even fearful of perceived consequences of ILBP (e.g. an inability to conceive) and perceived methods of injury (e.g. a car accident, a misplay in baseball) which they had no previous experience with at all. Therefore, participants seemed to have exaggerated negative interpretations of painful consequences for anticipated episodes of ILBP. Although this was partly due to previous experiences with ILBP, the uncertainty of ILBP consequences played a major role as well. The consequences of successive recurrences of ILBP were always variable and typically more debilitating, which made it difficult for participants to judge or predict how substantial the consequences of an anticipated bout with ILBP would be. Therefore, upon experiencing a recurrence of dissimilar pain consequences (e.g. long pain duration vs. longer pain duration, recovery without surgery vs. recovery with surgery, modified duty at work vs. extended work absenteeism) a decrease in pain-related certainty increased each participants' perceived susceptibility to experience a recurrence of ILBP of potentially harmful consequences they had not yet experienced. This susceptibility along with previous exposure to ILBP consequences was translated into identifiable fears through a process of catastrophizing. Overall, this group of CLBP patients' continued to live in fear of the consequences of re-injury following their very first experience with ILBP. This fear increasingly persisted over time and was associated with a permanent loss of mobility and functionality.

**Theme # 6 – Living alone with an injury: Isolated from others and by others**

Theme 1 demonstrated a remarkable feature of the CLBP experience. Although participants typically experienced TLBP on a day to day basis, the level at which each participant focused on ILBP avoidance during this time was quite substantial. Participants needed to constantly engage in a set of vigilant procedures in order to avoid the onset of ILBP. The internal nature of their struggles created a highly personalized and individualistic form of suffering. However, experiencing episodes of ILBP subjected participants to a form of suffering that others (including health care professionals) had difficulty understanding. Furthermore, such pain temporality incapacitated participants and restricted them from performing regular activities. Prolonged exposure to both TLBP and ILBP combined to create an isolating experience, as all participants suffered alone with their pain. Each participant was reluctant to express their pain in an attempt to keep their personal agony a private matter and to avoid being perceived as weak. However, each participant also experienced feelings of isolation due to a lack of understanding from others, which of course would only reinforce their reluctance to express their suffering to others. The following sections will outline and explain how participants isolated themselves from others and how participants were isolated by others which created the isolating experience of living alone with an injury.

Isolated from others

All participants directly contributed to their own isolation and loneliness as they were reluctant to admit or express their suffering. For many participants, living with CLBP was a private matter they felt others need not know of. For example, Marissa would rather suffer alone then have anybody think something was wrong

with her:

> *"so I have learned to just hide the pain because I don't want people to know, even though something is wrong with me (8; 13; 8)."*

The same could be said for Joanne:

> *"because at work you keep it under control and you don't want to show your pain or suffering (6; 11; 30)."*

In the case of Keith, he worried that others would perceive him as a liability so he was reluctant to express his CLBP to others:

> *"I hope I'm never seen in these terms but I hope no one sees me as a liability because that would be pretty shitty. Um...I mean just the idea of being a liability....nobody wants to be seen as a liability and you just think of the elderly and you know, what kind of – maybe they feel some guilt for having their children take care of them when their not able to take care of themselves. So you try not to talk about your back pain and when you are hurting, you keep it quiet unless you really need help (11; 5; 28)."*

Maureen had tried to express her suffering in the past, but the invalidating response from her coworkers influenced her decision to hide her CLBP:

> *"yah know, experiencing what happened at work. After what happened there, I don't want to burden others with it. No, in fact I don't want others to know, so I try not to tell anyone about it, so I just hide it for the most part (3; 13; 11)."*

It is interesting to note that when these participants were capable of functioning normally, they tended to hide their pain from others, in an attempt to avoid creating the illusion that something was wrong. However, in Jacob's case, he would rather avoid people or certain situations altogether for the sake of preserving his TLBP, which he found to be isolating in itself:

> *"Well...um...I guess just by being more restrictive in what I do and if isolation comes up, that's where it is, because restricting in what you do, means you don't partake in things you use to or you don't work with the crowd as much (10; 11; 9)."*

Much like the previous cases, when Monique and Steven were functionally able, they would rather suffer in isolation than admit or express their pain and suffering to others. However, these two also felt inclined to fake a quality of life they did not have to further disguise their CLBP. For Monique this was important in the classroom:

> *"A lot of it is faking it – you know that statement fake it till you make it. That means a lot, it's very true. If you look the part, if you look like your feeling good, if you put on a reasonable facsimile of being together, people are going to think that's, that's you and that's important because I don't want people to know I'm in pain (2; 11; 43)."*

Steven engaged in a similar procedure to ensure people perceived him as the same person he was before his experiences with CLBP:

> *"I tried to display the same person that I was or that I always have been to others and just really make it look like there really just wasn't anything going on because I really didn't want anyone to know (4; 10; 46)."*

Some participants associated 'pain expression' with 'pain complaining' and thus, would feel ashamed in admitting their CLBP to others. Michelle felt that complaining was a form of weakness. She was ashamed of being weak and this forced her to conceal her pain from others:

> *"I don't want to talk about. I don't feel like explaining it to people or talking about it because I feel like I'm complaining and I don't want people to see me as weak (1; 12; 27)."*

Edna expressed a desire to be perceived as strong, as her insecurity for being perceived as weak forced her to hide her CLBP:

> *"It bothers me, I don't like anybody talking about, you know. I always change the subject. Like: 'how are you doing?' 'Yah I'm good...everything great Like what am I gonna say? You know what I mean? Like why do we want people to feel sorry for us? Like I don't understand that. Like, you want to be strong (5; 14; 8)?'"*

Brittany thought that telling her coaches about her CLBP would be misinterpreted by her teammates as an attempt to get special treatment and thus, decided to hide her CLBP from her baseball team:

> *"So I started to stop telling my coaches it was really bad, so this way my teammates wouldn't know and they wouldn't think I was getting special treatment. Because I hate that, I hate when people get special treatment for something and I didn't want to be one of those people (9; 7; 22)."*

Gary explained how he would likely not engage with or express his CLBP to people who did not already know and understand his condition. This ultimately isolated him from others by inhibiting his ability to make new friends and meet new people:

> *"so I it's a relief when I don't have to explain myself all the time and...this is prolly why I don't make a lot of new friends (7; 9; 32)."*

This was another example of how the inability to express one's CLBP can be isolating, as during times when participants were physically able to partake in activities alongside others without CLBP, they felt inclined to hide their pain and suffer alone.

<u>Isolated by others</u>

Although each participant contributed to their own isolation, it was through a lack of understanding that others contributed to each participant's isolating experience as well. This lack of understanding was portrayed through insufficient medical and family support and a lack of believability from those who perceived the participants' CLBP to be illegitimate.

Both a lack of medical and family support contributed to feelings of isolation. Some participants engaged health care professionals on a regular basis to help

establish a routine for managing their TLBP. In some cases, an inability to establish a successful routine created an isolating experience. Michelle engaged physiotherapy in the hopes of controlling and reducing her TLBP, yet their inability to help reinforced feelings of aloneness:

> *"They didn't do anything for me, I felt completely lost. I was like uh: 'No...nothing your doing is helping me.' Some of what they did made it worse. That was very frustrating to me because it was very hard...I think for me and for probably a lot of people to be alone with an injury (1; 13; 37)."*

Gary committed substantial time to a chiropractor who he found to be unhelpful, this consequently contributed to feelings of isolation:

> *"So you go every day for that and ugh...that didn't seem to be working for me so I remember feeling very isolated at that time thinking; what's the point (7; 6; 16)?"*

For Joanne, suffering from TLBP at a time before complementary alternative medicine was popular restricted her ability to engage medical support systems or receive information on how to manage such pain:

> *"I didn't know anybody that could give me information on back problems and what do you do and how do you deal with it (6; 2; 42)?"*

These participants demonstrated that a lack of medical support during times of TLBP was very isolating, as oppose to a lack of medical support during times of ILBP, which was shown to be highly frustrating (theme 4).

A lack of family support also contributed to feeling of isolation for some participants. Monique received no spousal support during her struggles with CLBP, which forced her to fend for herself and ultimately destroyed her marriage:

> *"I would go as far to as say that the reason that I'm not with my husband is directly linked to how we coped with the back pain. When you know that person is not taking care of you and doesn't care – he's never taken a day off work to help me – he didn't, it was like; I was just to defend for myself (2; 8;*

*7)."*

Edna explained how she had no family support system in place to help manage her CLBP:

> *"You know, I've had my kids later in life so I don't have anyone to help me...I have to do this myself (5; 10; 25)."*

Keith's wife was a major part of his support system. His problem was that he had no other support systems in place and often felt alone when his wife would abandon him:

> *"Yah there are nights when my wife won't even sleep in the same bed as me...and that's tough because I will be in pain and I guess I'm a pain to her a lot of times and she's like my rock sometimes yah know. So when she leaves the bed, I always feel pretty alone and just crappy (11; 5; 31)."*

A lack of believability from other people was another major contributing factor for how participants felt isolated by others. Marissa felt others would always discredit the suffering associated with CLBP unless they were to experience it themselves:

> *"you can tell them but you almost feel like, I've told you this a 100 times - are you listening? If they can't experience it - its like I can't pinch you and that doesn't feel anything like pain does. I can't - unless I physically injure you, you will never know the feeling of what it is like (8; 11; 42)."*

She later reiterated how the perceived illegitimacy of her illness amongst others made it difficult for her to relate to others:

> *"...nobody believes how much pain you're in, so you can't tell them and no one can take it away (8; 11; 39)."*

Jacob re-emphasized Marissa's sentiments, as he described a shared understanding for CLBP only within the cult of people who experience it:

> *"...yah people don't really get it....its almost something that people of your own kind (people with CLBP) will understand so it's not something you can openly discuss with a lot of people (10; 12; 27)."*

One major reason people seemed to discredit the legitimacy of the CLBP participants experienced on a daily basis was because these participants lacked any sign of physical disability, particularly during times of TLBP. This was the foundation for some of the alienating experiences that isolated certain participants. Brittany felt alienated by her baseball coach and teammates who did not believe she was injured:

> *"but pretty much I kept it to myself because no one really took it on. They just dismissed it and said get over it (9; 4; 6)."*

Maureen recalled how her return to work from sick leave due ILBP created tension, as there was no visible sign of a disability upon her return:

> *"Um...when I went back to work there was tension because again, you don't see a cast, you don't see crutches, you don't see a physical difference when someone has a back pain (3; 9; 40)."*

Maureen's co-workers did not believe her CLBP was legitimate and their insensitive and hostile behavior ultimately alienated her from the staff and forced her resignation:

> *"let's put it this way; I left there. I gave them my notice and got another job out in Burlington because it was the disrespect. Yah know because I don't mock you, question you, ya know, when you have something wrong with you (3; 9; 44)."*

Steven felt alienated from nearly all people who could not understand how a seemingly physically fit young man could possibly be experiencing CLBP:

> *"Right and yah, and I think that's where some alienation would come in because some people would be like: 'You know what man; you don't even look like you have a problem. I mean, look at you, like what are you complaining about, you don't have anything to complain about, your fine.' And it got to a point where hardly anyone believed I had a problem, so I was kinda on my own (4; 15; 40)."*

In all of these cases it was either a lack of support or a lack of believability that contributed to the isolating experience during times of both TLBP and ILBP.

However, an overall lack of understanding from the support groups and social networks of the participants was the fundamental reason for why participants felt isolated.

Summary

The mechanisms contributing to the isolating experience of CLBP were complex, given the intrapersonal and interpersonal manifestations. Participants contributed to their own isolation as they all reported an inability to express their suffering to others. This reluctance seemed to be influenced by a desire to conceal their CLBP. However, participants clearly felt isolated by others from a lack of understanding that was portrayed by insufficient medical and family support and an inability to establish their suffering as legitimate and believable.

When experiencing TLBP, participants were capable of functioning quite normally and typically lacked any sign of physical disability. This increased the tendency of others to discredit their pain and suffering, which inevitably created an alienating and isolating experience for some. On the other hand, several participants were reluctant to express their pain because they did not want others to know. It is probable that the aforementioned characteristics of TLBP (a lack of visible disability, ability to function normally) may have significantly influenced this decision. In other words, participants likely would not have wanted others to know about their TLBP if they felt others had good reason to discredit their suffering. In some cases, previous exposure to deligtimization may have reinforced such concerns, increasing each participant's likelihood to conceal their TLBP. Regardless, it is clear that not only were feelings of isolation manifested during times of TLBP, but the characteristics of

such pain may have also directly contributed to the isolation some participants experienced. However, lack of support from family, friends, and coworkers during and immediately following episodes of ILBP also lead to feelings of alienation and isolation in some of the participants. Finally, some participants felt that only those with a shared understanding of CLBP (through experiencing it themselves) would understand their situation, which is why living with CLBP was altogether an isolating experience. Overall, it was clear that both the participants themselves and those around them played key roles in the isolating experiences of CLBP. Each participant's inability to express their pain, combined with a lack of understanding amongst the support groups and social networks of the participants, created an isolating experience which compelled participants to suffer individually and alone with their CLBP. Essentially, feelings of isolation developed and persisted as each participants journey with CLBP progressed over time.

**Theme # 7 – A self concept defined by pain – "Low back pain is a part of who I am"**

All participants expressed the idea that living with CLBP ultimately modified their self-concept[15], as all participants integrated their pain to represent a part of who they had become and likely would be for the rest of their lives. Participants expressed an altered self-concept defined by pain and suffering through descriptions of their continual everyday CLBP, the perceived inevitability of their CLBP, and the perceived normalcy of their CLBP.

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[15] Self-concept, sense of self and identity are often used interchangeably in the literature as they most often refer to a stable but dynamic collection of core beliefs, constructs, affects or cognitions that are utilized by the individual to define themselves both privately and in their presentation to the outside world (Osborn et al., 2006).

Both Edna and Monique expressed the idea that experiencing CLBP for a prolonged period of time contributed to an altered self-concept. For Monique, CLBP conquered what was once a normal life and subsequently altered who she had become:

> *"No. No. I was just a normal person, normal life. Everything was – well ya know well as normal as you could be. And ever since that (the injury), everything has just shifted, everything in my life changed, pain has now become a part of my life and a part of me (2; 17; 3)."*

The same could be said for Edna who became accustomed to living with CLBP:

> *"... I never woke up a day without the pain but I just learned to live with it. It's just been part of who I am (5; 3; 28)."*

Keith felt he could no longer contribute in the same way and that CLBP had taken over his life. Although he wasn't ready to concede that things would never change, he felt CLBP was now a part of him:

> *"I will carry it through the rest of my life and it's just or what I have to deal with. Its part of who I am I guess, but I still hold out for new research and new developments in lower back medicine and I hope that something is found that will help me out....hopefully sooner than later (11; 7; 6)."*

For some participants, experiencing CLBP everyday combined with the inevitability of long-term pain and suffering to catalyze a self-conceptual transition. Gary admitted it was these factors that ultimately changed the way he perceived himself:

> *"But now I have to be careful because I do have the back problem. And ...actually...that's probably the biggest change in the way I see myself because I always have low back pain and this is a part of who I am and probably will be for the rest of my life (7; 11; 43)."*

Brittany also made a direct connection CLBP and her altered self-concept:

> *"Unless I go for surgery it's always going to be there and will always be a part of me (9; 3; 26)."*

Maureen's description of immedicable CLBP reinforced the perception of inevitable suffering, which of course combined with her experiences of everyday CLBP to alter the way she perceived herself:

> *"Chronic back pain is part of me now. It's who I am now, its part of my everyday life. It's not like a bad pair of shoes, where you can get rid of it. I mean its there and I have to deal with it (3; 15; 2)."*

Jacob was confident that CLBP would always be a part of his life and that those close to him would confirm this notion:

> *"Yup, that's a part of life, a part of my life. The people who know me know its there and that it always will be (10; 13; 29)."*

Some participants portrayed a self-concept defined by pain in their description of personal experiences with CLBP and suffering, which they considered to be quite normal. These participants became accustomed to CLBP and in the case of Michelle, prolonged and continual pain actually desensitized her perceived level of suffering:

> *"and I think sometimes too that I don't even realize how sore it is because I've gotten use to how it feels so I don't even realize... because pain is a part of my life now...a part of me (1; 7; 5)."*

Pain was so much integrated into Joanne's life; she actually regarded CLBP as normal:

> *"my husband would say: "Are you in pain? Is your back bothering you?" And I'd say: why, why do you ask?" And he'd say: "well you have a strained look on your face." And I'd say: "yah it's bothering me but ya know that's normal." For me that was normal, pain was just a normal part of my life (6; 6; 4)."*

Continual exposure to everyday CLBP helped Steven develop a high tolerance for pain and suffering, as he modestly downplayed the significance of his suffering:

> *"It's really not that bad of a pain, like its barely even moderate, to me, but I think that may be because I'm so use to it, so the that pain is pretty much*

> *normal to me now cause its pretty much been a part of my everyday life. So I'm sure others might think its worse (4; 4; 22)."*

CLBP was a part of Steven's everyday life and thus, very normal to him. Marissa and those close to her accepted CLBP as a permanent fixture in her life, which again contributed to a perceived normalcy of pain and pain related behavior:

> *"People are use to me. If I get in one of my moods the kids will understand. They understand that pain is a part of me and quite normal for me and I've gotten use to it too...so that's fine (8; 11; 23)."*

Summary

All participants expressed the idea that living with CLBP ultimately modified their self-concept, as all participants felt CLBP represented a part of who they had become. Although some participants expressed these ideas directly in their interviews, others illustrated this through their description of the perceived normalcy of pain. It is clear that living with TLBP everyday interrupted by periods of ILBP for a prolonged period of time can dramatically alter ones ego. In all cases, a continual exposure to CLBP was the culprit for the self-conceptual shift, while in some cases; the perceived inevitability of a future was also a factor. These accounts were a testimony to how living with CLBP can fundamentally alter one's self-concept, as over time, participants' progressively integrated their pain to represent a part of who they had become and likely would be for the rest of their lives.

## Summary of All Themes

The CLBP experience was characterized by persistent TLBP interrupted by periods of ILBP, as participants regarded their pain as controllable, manageable, and tolerable or uncontrollable, unmanageable, and intolerable. Furthermore, patient reactions to CLBP were specifically related to and contingent upon these varying

forms of TLBP and ILBP. For nine of the participant's the CLBP experience commenced with an episode of ILBP, which eventually subsided into a TLBP that would continually persist until the next recurrence. Maureen and Steven were the only participants who experienced the onset of TLBP first, before succumbing to an episode of ILBP.

Following the recovery of an experience of ILBP all participants felt susceptible to experience another. Their perceived susceptibility to experience a recurrence led participants to engage in the continual pursuit of a permanent pain consciousness, to ensure that they were continually aware of and avoiding all chances for a recurrence of ILBP. An increased perceived susceptibility to ILBP and the desire to avoid a recurrence of ILBP were reinforced following the recovery of each successive recurrence of ILBP. All participants experienced an average of two recurrences of ILBP for a count of three altogether. During their experiences of ILBP participants became depressed on account of prolonged physical helplessness and uncertainty of pain duration. Since participants were unable to help themselves, they engaged the medical community to find help with relieving their ILBP. However, the uncertainty of pain patterns, unrealistic pain expectations, and a lack of control inevitably created a frustrating experience for all of the participants who expressed contempt towards the medical system. Depression and frustration were typical responses to recurring ILBP that persisted only during times of such pain. However, as recurrences became more frequent; a fear of the perceived consequences of anticipated ILBP increased in the minds of the participants. This was due to negative exaggerated interpretations of pain based on previous exposure to recurring ILBP and

each participant's perceived susceptibility to experience increasingly harmful ILBP consequences not yet experienced. These fears were based on the idea of permanent restriction; including a loss of mobility, functionality and independence, which of course influenced each participants desire to pursue a permanent pain consciousness and avoid ILBP.

Although uncertainty of ILBP was not included as a theme in this analysis, it was undoubtedly foundational in the development of other themes. For example, feelings of depression were directly related to the uncertainty for which ILBP persisted. An uncertainty for how to manage such pain motivated participants to seek medical help, however, an uncertainty in pain patterns made it exceedingly difficult for health care professionals and patients to establish successful strategies for managing ILBP; which subsequently frustrated participants consistently throughout their experiences with such pain. Finally, an uncertainty for the severity of anticipated consequences of ILBP formulated each participants perceived susceptibility to experience increasingly harmful ILBP consequences not yet experienced and this partly contributed to the exaggerated negative interpretations of ILBP that participants lived in fear of experiencing.[16]

Experiencing everyday TLBP interrupted by periods of ILBP contributed to gradual developmental changes in each of the participants. For example, each participant became more isolated as their CLBP persisted. This was partly of their own accord, as they were reluctant to express and share their suffering with others,

[16] For the readers benefit a metaphorical conception of ILBP as torture due to the uncertainty of such pain, so as to further understand the influence of uncertainty on psychological well-being, has been provided in section 1 of the data manual.

however, others also contributed to this isolation through a lack of support and a lack of believability. Participants also progressively integrated pain and suffering as a part of their self-concept over time as they changed from a "normal" pain free person, to that of an "injured" person. They expressed this altered self-concept through descriptions of their continual everyday CLBP, the perceived inevitability of their CLBP, and the perceived normalcy of their CLBP. Finally, as CLBP progressed, each participant felt as if they were living with a weakness. This weakness was perceived to be the lower back itself, as all participants felt that a "weak low back" inherently predisposed them to CLBP, operated as a mechanism for expressing all forms of stress and that physically eliminating this "weak spot" would end their pain and suffering. Furthermore, this perceived weakness helped to reinforce feelings of personal susceptibility for each participant.

## Chapter 5 – Discussion

The lived experience of CLBP was characterized by persistent TLBP interrupted by periods of recurring ILBP. Recurring ILBP contributed to recurring bouts of helplessness, depression, frustration with the medical system and increased fear based on the perceived consequences of anticipated recurrences, all of which were mediated by the uncertainty of pain during such time. Meanwhile, during TLBP all participants felt susceptible to experience a recurrence as they vehemently pursued a permanent pain consciousness in an effort to be forever aware of and avoid all possibilities of a recurrence of ILBP. As CLBP progressed, participants began to feel as if they were living with a weakness, became isolated from those without CLBP and integrated pain into their self-concept to represent a part of who they had become and likely would be for the rest of their lives.

Psychological risk factors are significantly implicated in the development and maintenance of CLBP, specifically depression, catastrophizing, fear-avoidance behavior, anxiety, and somatization (Linton 2000; Hasenbring et al., 2001; Pincus, Burton, Vogel, & Field, 2002; Dunn et al., 2004), all of which were previously identified as psychological research themes. In light of the abundance of recent literature, the psychological connection to CLBP is still somewhat ambiguous. This is evidenced by the clinical mismanagement of CLBP (Murphy et al., 2007) and by psychological interventions on CLBP that are either inefficacious (vanTulder et al., 2001; Nielson & et al., 2001) or although beneficial in comparison to traditional medical rehabilitation, still perpetuate the need for an improved understanding of the

psychological response to CLBP (Morley et al., 1999; Guzman et al., 2001; Hoffman, et al., 2007). The objectives of this study were to further understand the psychological response to CLBP, while highlighting the role of each psychological research theme (depression, catastrophizing, fear-avoidance behavior, anxiety, and somatization) in that response. Therefore, in the sections that follow, all emergent themes of the analysis and the five psychological research themes (depression, catastrophizing, fear-avoidance behavior, anxiety, and somatization) will be examined together in an integrated discussion that clearly and succinctly articulates each participant's CLBP experience in relation to extant literature. This will help to facilitate an improved understanding of the psychological response to CLBP and suggest topics in need of future research. The study's limitations are documented at the end of this discussion.

**Everyday tolerable LBP vs. periodic intolerable LBP**

It has been widely believed that most episodes of LBP will be short-lived with 80% to 90% of attacks resolving in about 6 weeks, irrespective of the administration or type of treatment and only 5% to 10% of patients will develop persistent LBP (Shekelle, Markovich, & Louie, 1995; Anderson & Svensson, 1983; Croft, Papageorgiou, & McNally, 1997). Thus, LBP has typically been classified according to length of time since pain onset (International Association for the Study of Pain, 1986; Frymoyer, 1988; van Tulder et al., 2002b). However, the traditional view of LBP consisting of single episodes of acute and chronic LBP seems inadequate (Von Korff et al., 1996; Manchikanti et al., 2009). LBP is a condition that tends to relapse with many patients experiencing multiple episodes (Gureje, Simon, & von Korff, 2001; Andersson, Ejlertsson, Leden, & Rosenberg, 1993; Eriksen, Ekholm, Sjøgren,

& Rasmussen, 2004; Kadam, Thomas, & Croft, 2005; Cassidy, Côté, & Carroll, Kristman, 2005; Hestbaek, Leboeuf-Yde, & Manniche, 2003) and studies have shown that LBP is still present after long periods of time (at least after 12 months) in an average of 50% of patients (Gureje et al., 2001) and most recently in a range of 24% to 33% of patients (Stanton et al., 2008). Yet, it is unclear when LBP becomes a chronic problem, as a standard definition of CLBP and how it develops is not yet available and remains a topic of controversy (van Tulder et al., 2002b; Dunn et al., 2004; Manchikanti et al., 2009)

Participants' experiences of CLBP helped to enlighten this matter as each participant's CLBP was not one simple episode of acute LBP turned chronic. Rather it was recurring episodes of debilitating ILBP within the context of persistent TLBP. Such a conceptualization of CLBP disassociates from traditional duration-based definitions and fits more suitably with contemporary accounts of the fluctuating, intermittent and viable course of CLBP (Von Korff et al., 1996; Croft et al., 1997 Manchikanti et al., 2009). However, the experience of persistent TLBP interrupted by periods of ILBP suggests that CLBP will always be either tolerable or intolerable, regardless of the fluctuating and intermittent course in which it progresses. In this sense, participants advocated a dichotomist perception of CLBP (tolerable vs. intolerable), but it important to recognize that this did not infringe upon the possibility for unique and individual experiences. Firstly, TLBP and ILBP were only perceptions of a type of pain based on their ability to manage and control such pain. Therefore, two people experiencing "tolerable" LBP could very well be experiencing two different types of physical pain. Secondly, although each participant

conceptualized the CLBP experience to be persistent TLBP interrupted by periods of ILBP, the manner in which this persisted (e.g. the number of recurrences, the length of a recurrence, the time in-between recurrences, the fluctuating intensities of TLBP etc) was unique for each individual. Therefore, dichotomizing CLBP as tolerable or intolerable allowed for the possibility of individual differences in physical pain sensations considered to be equally tolerable or intolerable and for individual differences in the course and progression of each participant's CLBP. In light of the possibility for these individual differences; all participants' experiences of ILBP, TLBP, and CLBP were associated with the same psychological, emotional, and behavioral reactions.

**Depression and helplessness**

All participants discussed how periods of ILBP were extremely discouraging and depressing, which supports Von Korff et al. (1996) and Bener et al. (2006) suggestion that degree of pain is associated with severity of depression, as depression was not accounted for during times of TLBP. In this study depression was directly related to feelings of physical helplessness and uncertainty. Physically, participants felt helpless as the effects of ILBP were incapacitating, immobilizing and debilitating. This supports De Souza et al. (2007) finding that CLBP patients express feelings of helplessness as a result of their physical limitations. However, participants experienced such helplessness in an aura of uncertainty for how long it would persist. Therefore, both the loss of physical functioning and the uncertainty of pain duration during ILBP combined to create feelings of helplessness, which ultimately produced a depressing experience during each recurrence of ILBP. The more recurrences of ILBP

a participant endured, the more depressing their experiences were. However, depression has been found to be associated with less successful treatment outcomes, as misdiagnosing or mistreatment can influence levels of depression (Burns et al., 1998). During times of TLBP participants invested in preventative lifestyle treatments (e.g. regular exercise) to help decrease the likelihood of a recurrence with ILBP. Therefore, it is possible that inefficacious preventative measures may have partially attributed to feelings of depression accounted for during recurrences of ILBP (since they did not prevent the recurrence); however, this is a topic that requires further investigation. Regardless, results of this study are similar to Bowman (1991), as she felt the meaning of CLBP could be perceived through a decreased quality of life that was evidenced by major feelings of helplessness and despair, which resulted from a continuous cycle of unremitting pain.

Clearly there was a strong connection between helplessness and the onset of depression. However, significant somatic disturbances and uncertainty of pain duration were underlying factors in this connection and it was prolonged exposure to these antecedents which ultimately formulated feelings of depression. Consider the manner in which feelings of helplessness and depression initiated and dissipated. Prolonged exposure to physical pain indicated to the participant that they were now entering a period of ILBP. As ILBP persisted, an uncertainty of pain duration emerged. Therefore, the onset of prolonged physical helplessness (via prolonged and debilitating pain) was foundational in the development of pain-related uncertainty, which then initiated the onset of depression. This explains why participants were not depressed during temporary periods of increased TLBP. Somatic disturbances could

become highly-severe during times of TLBP but they were always short in duration (e.g. 24 hour low back spasm) and thus, an uncertainty for pain relief would never materialize. In this sense, it seems as if physical helplessness (via debilitating pain), the uncertainty of pain duration (via prolonged debilitating pain) and depression (via physical helplessness and uncertainty of pain duration) were related to one another by cause and effect and operated within a chain of sequence. However, more research on this connection is needed, as it is unclear how long participants have to experience debilitating ILBP before a sense of uncertainty for pain relief settles in. Corbett et al. (2007) found that increased control over one's LBP can improve psychological well-being and increase feelings of hope. During times of ILBP participants had little control over their pain and seemed to lose hope for successful recovery, which is evidenced by their expression of helplessness and depression during such time. Therefore, it is imperative that future research examines potential mechanisms for establishing greater control during times of ILBP as this would likely offset feelings of helplessness and subsequent depression.

**Frustration with the medical system**

During times of ILBP participants would engage the medical community to find help with relieving a pain they were unable to manage on their own. However, no participants were able to establish a successful routine for managing or relieving ILBP, which often led to increased feeling of frustration and disdain for the medical system. Uncertainty of pain, unrealistic pain expectations, and the uncontrollability of pain were three underlying factors that influenced each participant's negative appraisal of health care. Anger appears to be a salient feature of the CLBP experience

that is frequently suppressed as there is rarely anyone at whom it can be directed (Fernandez et al., 1995; Walker at al., 1999). However, this did not seem to be the case, as all participants expressed their frustration with health care professionals through a perceived lack of support (via ineffective treatment), ineffective communication and a lack of understanding between themselves and their health care professional.

A lack of pain relief from health care professionals during ILBP was a main source of frustration for each of the participants. They expected an immediate diagnosis and immediate pain relief and became frustrated with their health care professionals when they were unable to do so. This appears to be a common source of frustration for those with CLBP (Campbell et al., 2007; Verbeek et al., 2004) even though accurate diagnosis, leading to specific, targeted treatments of patients with spinal pain has typically been elusive (Hainline, 1995; Nachemson, 1992; van Tulder et al., 2002a; Murphy et al., 2007) However, uncertainty seems to be a significant underlying factor for why diagnosis and specific targeted treatments of CLBP are hard to come by. Uncertainty in regard to the onset of pain, duration of pain, intensity of pain, and time in-between pain episodes, made it difficult for participants and health care professionals alike to develop clear pain patterns/expectations. This in turn made diagnosing, managing, treating and relieving ILBP a formidable challenge for health care professionals, thus increasing patient frustrations. Therefore, attempts to increase pain-related certainty would benefit both health professionals and patients alike; through the likelihood of improved clinical outcomes and reduced frustrations.

Previous research has indicated that CLBP sufferers express a genuine disdain for the medical system's tendency to only acknowledge the physical aspect of pain (Fernandez et al., 1995; Walker at al., 1999; Campbell et al., 2007) and that patients feel anger and frustration in the absence of effective communication (Verbeek et al., 2004). Therefore, it is no surprise that participants were frustrated with ineffective communication and a lack of patient understanding on behalf of health care professionals. In their examination of the health care professional-patient partnership in treatment of CLBP, Slade, Molloy, and Keating (2009) suggested that CLBP patients were frustrated with not being provided adequate pain relief and not being listened to and understood by health care professionals. Results from this study reaffirm Slade et al. (2009) findings in that participants expected health care professionals to not only to relieve their ILBP but to facilitate this treatment in a way that was empathetic and understanding of their particular situation. This is a major clinical challenge which requires a refocusing of treatment to a 'client-centered' rather than 'pain-centered' approach (Main & Spanswick, 2000, pg 17.). Therefore, more research on patient/ health care professional needs/expectations is required to promote a shared understanding between the two that will help facilitate greater success in pain management and reduce patient frustrations with the medical system.

A lack of control influenced each participant's negative appraisal of the medical system. During times of ILBP, participants had practically no involvement in decreasing pain intensity and had to rely completely on pain medication, a general practitioner, a neurologist, a surgeon etc, to relieve their pain. Walker et al. (1999) expressed the idea of how CLBP patients can become trapped in "the system" which

encourages powerlessness, helplessness and anger (p. 623). This was the case for many participants in this study as they willingly adopted their health care professional's advice to passively invest "in the power of the body to heal itself" (e.g. bed rest, pain medication) despite continued frustration with such intervention. A lack of control or an inability to manage their ILBP independently inclined participants to re-engage the medical system rather than challenge these standard and passive medical protocols. Regardless, participants were continually frustrated with a lack of medical support and it seemed somewhat surprising that they would continually re-engage the medical system for help. There are various speculative reasons for this, all based on extant literature. Firstly, Campbell et al. (2007) and Walker et al. (1999) suggested that unrealistic expectations to find a readily available cure fuels a patient's sense of agency to engage and re-engage the medical system. All patients believed medical intervention would relieve ILBP and thus, were continually re-engaging the medical system for help during such time. Secondly, research by Walker et al. (1999) and Glenton (2003) indicated that CLBP is not a justified illness in the medical community and patients must work to establish the authenticity of their pain. Thus, it is also possible that participants continually engaged medical treatment despite previous frustrations, in an attempt to justify their suffering to others and themselves. Thirdly, individuals may have re-engaged medical treatment to achieve the status of the "sick role" to gain acceptance of their pain by others and decrease feelings of stigmitzation (Frankenberg, 1980; Glenton, 2003). More research is needed to determine which of these motivations is most salient to CLBP patients who continually re-engage the medical system, despite recurring frustration.

**Personal Susceptibility**

All participants felt extremely susceptible to experience a recurrence of ILBP following the recovery of their initial bout with such pain. This susceptibility was reinforced following each recurrence of ILBP. In Toombs (1993) explication of the meaning of illness, she states that the onset of illness brings one face-to-face with personal vulnerability[17], as the loss of control that is intrinsic to the experience of illness is accompanied by an acute awareness of the unpredictability of the familiar world. Although participants devoted much time and energy into preventing ILBP, they all conceded that a recurrence could happen at any time. Therefore, participants had to live with the fact that at any time they could become temporality incapacitated by debilitating ILBP. Furthermore, Toombs (1993) explains that when it can no longer be assumed that things will continue as they have in the past, the person who is ill finds prior assumptions and knowledge about the familiar world to be strangely inadequate for interpreting existential crisis, which of course further contributes to personal susceptibility. Participant assumptions about the relative safety in performing everyday activities, movements and postures without inciting ILBP were no longer certain and the knowledge they had established over time about which movements were unlikely to contribute to ILBP was now inadequate. This of course increased their perceived susceptibility to experience recurrences of ILBP, which participants addressed through their pursuit of a permanent pain consciousness (see page 140) and which also factored in on each participants altered self concept (see page 149). Although Toombs (1993) research on vulnerability applies to people of all

[17] Toomb (1993) uses the term vulnerability when referring to what the researcher of this study has annotated susceptibility. Thus, the terms should be regarded as inter-changeable.

illness, it helped to elucidate the philosophical orientations and implications of susceptibility for participants in this study. Thus, more research of similar focus on specific subgroups of CLBP would be beneficial.

Although each participant's personal susceptibility was established and reinforced by recurring episodes of ILBP, it was further perpetrated by the perception that they were living with a weakness and thus were inclined to suffer. Whereas, CLBP patients in Turk et al. (2008) conceptualized limited functional ability as a weakness, participants in this study conceptualized their lower backs as a weakness, which in turn increased their perceived susceptibility to pain and suffering. Some participants felt this weakness inherently predisposed them to CLBP. Others felt their lower back's operated as a mechanism for expressing all forms of stress, thus increasing their susceptibility to increased TLBP. Finally, some participants felt physically eliminating the "weak spot" would end CLBP once and for all. The latter two exemplify a mind-body dichotomy as participants felt their bodies were a vessel for expressing stress created by the mind and that by physically eliminating the body (the low back) they could eliminate the stress. This is peculiar considering that participants in this study and others have expressed frustration towards health care professionals who advocate a mind-body dichotomy (separate the mind from the body) during treatment of their pain (Fernandez et al., 1995; Walker at al., 1999; Campbell et al., 2007).

The consequences of successive recurrences of ILBP were always variable and typically more debilitating and as Croft et al. (1997) suggest, this is not surprising as recurrences occur more frequently and are more severe if patients have had

frequent or long-lasting LBP complaints in the past. When participants experienced recurrences of dissimilar pain consequences (e.g. long pain duration vs. longer pain duration, recovery without surgery vs. recovery with surgery, modified duty at work vs. extended work absenteeism) a decrease in pain-related certainty made it difficult for them to judge and predict the potential consequences of their next anticipated bout of ILBP. Therefore, not only did participants feel susceptible to experience a recurrence of ILBP following each bout with such pain, but increasingly devastating, successive recurrences of ILBP increased their perceived susceptibility to experience increasingly harmful pain consequences not yet experienced.

**Catastrophizing**

The susceptibility to experience a recurrence of ILBP with potentially harmful consequences they had not yet experienced was translated into the development of identifiable fears through a process of catastrophizing. The fears expressed by participants were based on perceived consequences of anticipated ILBP, including permanent immobility, restriction, and a loss of functionality, either directly (e.g. paralysis) or indirectly (e.g. inability to support family because of paralysis) (see next section). Although these fears were based on what they perceived would be permanent consequences of anticipated ILBP (e.g. no longer able to walk, in a wheelchair, parlayed, no longer able to support kids), their previous experiences with these consequences were only temporary (e.g. temporary loss of mobility, temporary loss of functionality, temporarily unable to support kids). Therefore, the fears expressed by each participant were based on exaggerated negative interpretations of anticipated ILBP consequences. Clearly, the formations of these interpretations were

somewhat influenced by previous experiences. However, a sense of uncertainty via increasingly devastating, successive recurrences of ILBP increased each participant's perceived susceptibility to experience harmful pain consequences not yet experienced. Therefore, susceptibility to experience a recurrence of ILBP with potentially harmful consequences they had not yet experienced combined with previous exposure to ILBP consequences to help formulate exaggerated negative interpretations of anticipated ILBP consequences. These exaggerated interpretations of anticipated ILBP consequences increased over time and represented the fears expressed by participants during their interviews. This explains why the fear of being paralyzed would be more sensible to a person with CLBP who has experienced multiple recurrences of ILBP, than to a person recovering from a random and single bout of ILBP. Furthermore, these findings support preliminary evidence that pain catastrophizing may be considered a precursor of pain-related fear (Leeuw et al., in press; Vlaeyen, de Jong, Geilen, Heuts, & van Breukelen, 2002; Vlayen et al., 2000).

The fact that participants exaggerated negative interpretations of anticipated ILBP consequences supports the idea that catastrophizing is related to exaggerated responses to acute or in this case ILBP (France, al'Absi, Ring, & McIntyre, 2002; Sullivan et al., 1997). However, the CLBP experience was characterized by recurring episodes of ILBP and thus, catastrophizing (and the factors which preceded it) helped facilitate the development and sustainability of fear throughout the entire CLBP experience. This supports preliminary evidence presented by Leeuw et al. (2007) review of the fear-avoidance model (FAM) of musculoskeletal pain suggesting that individuals with an increased susceptibility to catastrophizing may be less changeable

in their fear-avoidance beliefs than those without this susceptibility. Therefore, for clinical practice, it may be beneficial to screen for individuals with previous exposure to ILBP consequences, who feel susceptible to experience exceedingly harmful ILBP consequences not yet experienced. These individuals may require a different approach for addressing the role of fear and fear-avoidance beliefs than for those who have not experienced these variables.

**Fear of perceived pain consequences**

Participants lived in continual fear of suffering through the perceived consequences of an anticipated recurrence of ILBP. These fears were associated with the idea of permanent restriction; including a loss of mobility, functionality and independence. For example, six of the eleven participants lived in fear of losing the ability to walk (being in a wheelchair/becoming paralyzed). Three of these participants feared the method in which they perceived paralysis to occur (car accident). Five participants feared not being able to support those they cared about as a result of not being functional and independent. One participant even lived in fear of not being able to procreate. What made the fears expressed by participants in this study unique was that they were all based on the perceived consequences of anticipated ILBP. A large body of contemporary research has focused on pain-related fear, a central component of the FAM, (Lethem et al., 1983; Philips, 1987; Waddell et al., 1993; Vlaeyen et al., 1995; Vlaeyen et al., 2000) as a mechanism for the maintenance of CLBP and a risk factor for the development of CLBP (Leeuw et al., 2007). Pain-related fear can best be defined as the fear that emerges when stimuli that are related to pain are perceived as a main threat; including fear of pain, fear of work-

related activities, fear of movement and fear of (re)injury (Leeuw et al., 2007). In this study, expressions of pain-related fear were aplenty and mainly concerned with fear of movement, fear of leisure activities and fear of work-related activities. However, participant expressions of pain-related fears were only superficial representations of more profound and prolific fears. For example, Jacob was scared about twisting or bending in a way that would incite a recurrence of ILBP and this was based upon his fear of experiencing a recurrence of ILBP. However, the fear of experiencing ILBP was based upon Jacob's fear of not being able to support his wife and kids due to the incapacitating effects of ILBP. Therefore, Jacob's initial pain-related fear (fear of movement) was ultimately based upon a fear of the perceived consequences of anticipated ILBP (not being able to support his family). This was the case for all participants, as they expressed different pain-related fears throughout their interviews but when asked to describe what they were most afraid of, they all referred to perceived consequences of anticipated bouts with ILBP (being in a wheelchair, being paralyzed, not able to support others etc).

As Vlaeyen et al. (2000) explicated in their review of the FAM, the relationship between avoidance behavior and specific fears appears to be more complex than the model may insinuate. Questionnaires for the assessment of pain-related fear (including fear of pain, fear of work related activities and fear of movement/re-injury) are now available but they do not tell us what the individual is exactly fearful of (Vlaeyen et al., 2000). Therefore, new assessment methods are needed to identify the idiosyncratic aspects of fear and the essential fear-provoking stimuli in a particular patient, while the origin of pain-related fear merits future

research attention (Vlaeyen et al., 2000; Leeuw et al., 2007). Clearly all expressions of pain-related fear by participants in this study were based upon the perceived consequences of anticipated ILBP. Furthermore, whereas pain-related fear can best be defined as the fear that emerges when stimuli that are related to pain are perceived as a main threat (Leeuw et al., 2007), fear of anticipated ILBP consequences were long term concerns that gradually increased and were forever present in the minds of each participant. Therefore, not only it is important to recognize fear of anticipated ILBP consequences in patients with CLBP as a potential origin of pain-related fear, but it is imperative to consider the temporality of these fears and possible cumulative effects associated with long term, sustainable fear. For example, what effect does living with the fear of not being able to have children have on Maureen? How does this affect her outlook on marriage and procreation? What effect does this have on her spiritual health? How does this affect her courting behavior? Thus, further research needs to investigate fear of perceived consequences of anticipated ILBP as a culprit for pain-related fears and to investigate the effects of sustained and long term fear on physical, psychological and sociological well-being in those experiencing CLBP. This research could advance pain-related fear assessment procedures and improve patient understanding in regard to what exactly they are afraid of and how these fears implicate health and well-being within the biopsychsocial domains.

**A permanent pain consciousness**

Living with CLBP fundamentally altered the conscious thought and behavior of all the participants. Following their initial experience with ILBP, as TLBP persisted; all participants established a concern for avoiding the onset of another

episode of ILBP. This forced participants to be continually aware of their lower backs and any potential sources of ILBP as they were continually vigilant of bodily movements and continually anticipating perceived painful stimuli. Thus, the desire to avoid ILBP became an internal and permanent struggle in the minds of each participant during times of TLBP. Even though it was not possible to be permanently conscious of and forever thinking of ways to avoid a recurrence of ILBP, personal susceptibility reinforced their pursuit of a permanent pain consciousness. All participants felt susceptible to a recurrence of ILBP during times of TLBP. As Toombs (1993) previously explicated, when a person is confronted with a new and unique illness, they find prior assumptions and knowledge about their life before the illness to be strangely inadequate for interpreting existential crisis. This was the case for the participants, as their habitual ways of moving and thinking were no longer viable and had to be reconstructed to accommodate their CLBP. However, as Jacob articulated this was a very difficult thing to do:

> *"In teaching people a skill, the toughest part is getting them to unlearn their bad habits, because in times of stress, that's what's imbedded the deepest and that's what comes back, how to do it improperly (10; 6; 39)."*

Thus, even though participants strived to be permanently conscious of and forever thinking of ways to avoid ILBP; recurrences were inevitable. The fear of perceived consequences of anticipated ILBP also contributed to and reinforced each participant's pursuit of a permanent pain consciousness. Furthermore, the continual vigilance of bodily movements and the continual anticipation of and preparation for potentially painful stimuli are representations of the fear-avoidant and hypervigilant behavior resulting from their lived fear of the perceived consequences of anticipated

ILBP.

**Fear Avoidance Behavior and Hypervigilance**

During times of TLBP participants were continually vigilant of bodily movements as they attempted to ensure that all movements/postures were premeditatedly cautious, so as to prevent the onset of ILBP. Marrissa conceptualized this idea rather concisely:

*"I have to think before I do things, so I don't throw the back out again (8; 6; 24)."*

However, if certain movements or postures were thought to accentuate TLBP or to increase the possibility of a recurrence of ILBP, participants would avoid them altogether. Participants' were continuously looking for and anticipating potentially painful stimuli and planning ways to avoid or deal with them in advance. In some cases, this required participants to be hypervigilant towards perceived sources of pain within both their immediate environment and environments they anticipated to be in. If participants felt threatened by a perceived source of ILBP (e.g. slippery weather conditions), they would prepare a strategy for managing it (e.g. wear shoes with reasonable tread) or avoid the threat altogether (e.g. stay inside). Both a continual vigilance of bodily movements and the continual anticipation of and preparation for perceived painful stimuli were preparatory and/or avoidance strategies intended to prevent the onset of ILBP during times of TLBP.

The CLBP experiences of participants in this study offer some unique insight on the FAM (Lethem et al., 1983; Philips, 1987; Waddell et al., 1993; Vlaeyen et al., 1995; Vlaeyen et al., 2000). Firstly, the model suggests that pain-related fear leads to avoidance behavior and hypervigilance to bodily sensations and pain; however,

participant's indicated that susceptibility to ILBP was a major contributing factor in each participant's decision to endorse avoidant and hyperviligant behavior. Secondly, Leeuw et al. (2007) reported that it is unclear whether the association between pain-related fear and disability are mediated by avoidance/escape behaviors and/or hypervigilance, but hypervigilance and avoidance behavior often functioned as a cohesive unit for the participants in this study. Participants were continually selectively attending to perceived sources of ILBP within both their immediate and anticipated environments, before deciding whether or not these potential sources were manageable or to be avoided. Thirdly, the model suggests that engagement in avoidance behavior and hypervigilance helps to maintain a chronic pattern of disability. It was unclear whether this was the case, however, participants continually pursued a permanent pain consciousness throughout their CLBP experiences and they were continually endorsing both avoidance behavior and/or hypervigilance (through the continual vigilance of bodily movements and the continual anticipation and preparation for perceived painful stimuli). Therefore, it is possible that such behavior did in some way promote prolonged and continued disability. More importantly, if this was the case, participants would not have recognized it to be so. Participants believed that investing in hyperviligant and avoidant behavior was completely necessary for avoiding recurrences of ILBP and improving their physical health, even if it seemed silly or impractical. Thus, patient education on the risks and possible long term ramifications of hypervigilance and avoidance behavior may be necessary for those with CLBP. Finally, in addition to the onset of disability, frequent avoidance behavior may also contribute to a deterioration of physical fitness ("disuse

syndrome") (Verbunt et al., 2003). However, thus far only lower or equal daily life activities were found when comparing CLBP patients with healthy controls (Nielens et al., 2001; Spenkelink et al., 2002; Verbunt et al., 2001) and currently, neither lower physical activity levels nor the physical consequences of long-term avoidance behavior in CLBP patients have been unambiguously confirmed. Although participants in this study opted to avoid activities, exercises, and movements they considered would increase TLBP or contribute to a recurrence of ILBP, they all regularly invested in some form of physical activity to help establish and maintain control over their TLBP and to prevent future occurrences of ILBP. This supports Verbunt et al. (2003) findings that CLBP patients avoid activities they perceive will increase pain, but in general maintain their physical activity levels when compared to healthy people. This explains why CLBP patients can have serious functional limitations despite unaffected activity levels (Verbunt et al., 2003), which was the case for participants in this study. For example, John went for a walk and a swim every single day, despite having to use a back cushion to prevent pain whenever taking a sitting position.

**Anxiety**

In-between recurrences of ILBP all participants were certainly nervous and worrisome about the possibility of a recurrence. However, this was based on their fear of experiencing the perceived consequences of an anticipated recurrence of ILBP and their perceived susceptibility to experience such pain. Therefore, fear and susceptibility were foundational in the formation of any such anxiety, which opposes the diathesis-stress argument that CLBP exacerbates a genetic disposition to anxiety

(Polatin et al., 2000). It was not uncommon for participants to interchangeably express pain-related fear and pain-related anxiety (e.g. fear vs. worry of moving the wrong way) which at times made it difficult to distinguish between the two. Nevertheless, expressions of pain-related fear and/or pain-related anxiety were all based on each participant's fear of different perceived consequences of anticipated recurrences of ILBP, as fear ultimately consumed the minds of participants and influenced their pursuit of a permanent pain consciousness. Therefore, participants clearly expressed fear as the more salient and influential feature in their experiences of CLBP. Regardless, the tendency to associate fear with anxiety is not uncommon, considering that fear and anxiety are used interchangeably in the clinical setting (Leeuw et al., 2007) and in the FAM (Lethem et al., 1983; Philips, 1987; Waddell et al., 1993; Vlaeyen et al., 1995; Vlaeyen et al., 2000). However, there have been attempts to disassociate the two. Asmundson's et al. (2004) updated version of the FAM states that anxiety in the anticipation of pain leads to avoidance behavior, which in turn leads to disuse, disability, and depression. However, all participants clearly expressed a fear of perceived consequences of ILBP they anticipated would recur. That being said, expressions of anxiety were contingent upon and specifically related to fear of anticipated ILBP consequences, which supports the argument that although the distinction between anxiety and fear is theoretically correct, it is difficult to make in the context of chronic pain (Leeuw, et al., 2007). More research on the relation between the two would be useful for further understanding their combined and/or independent association with the response to CLBP.

**Living alone with an injury: Isolated from others and by others**

The mechanisms contributing to the isolating experience of CLBP were complex, given the intrapersonal and interpersonal manifestations. Participants contributed to their own isolation as they all reported an inability to express their suffering to others. This reluctance seemed to be influenced by a desire to conceal their CLBP. However, participants felt isolated by others due to a lack of understanding that was portrayed by insufficient medical and family support and an inability to establish their suffering as legitimate and believable. Bowman (1994b) phenomenological research on the reaction to CLBP also found participants to be isolated through a situation imposed by others or by conscious choice. Such experiences created a highly personalized and individualistic form of suffering for participants in this study, as they progressively developed a sense of isolation from those without CLBP.

Participants contributed to their own isolation through an inability to express their pain. When experiencing TLBP, participants were capable of functioning quite normally and typically lacked any sign of physical disability, a common feature of CLBP (van Tulder et al., 2002b). Therefore, it is possible participants felt others had probable cause to discredit their suffering and that this could be avoided by simply not telling others about their pain. The anticipation of stigmatization from others has previously been shown to coerce participants into suppressing feelings of anger towards unhelpful health care professionals (Fernandez et al., 1995; Walker at al., 1999). Therefore, fear of stigmatization may have influenced the suppression of pain and pain-related distress in the CLBP patients. Regardless, it is clear that participants did not want others to know about their pain. In some cases participants associated

pain expression with weakness, as admitting and expressing pain to others was considered shameful. This was reiterated in the work of Bowman (1994b) who found CLBP patients to be embarrassed about admitting their pain to others

Some participants felt isolated by those who could not help or support them; including health care professionals and family members. Meanwhile, other participants felt alienated by others who did not believe they were in pain; including teammates and coworkers. Overall, a lack of understanding from others contributed to feelings of isolation for each of the participants[18]. The inability of health care professionals to help diagnose and treat their condition left three participants feeling unsupported and isolated during the initial stages of TLBP. Four participants who had not received a clear diagnosis felt isolated when friends and family were unsupportive and insensitive. This supports Holloway et al. (2007) proposition that a lack of a diagnostic label and the invisibility of pain can be socially stigmatizing and make communication with family and friends very difficult. However, Holloway et al. (2007) also found that a 'work stigma,' can exist as a result of unsupportive and unsympathetic employers. Brittany's baseball coach and teammates and Maureen's boss and co-workers did not believe their pain to be a real problem and such stigmatization alienated them from their respective teammates/coworkers. Therefore, the lack of understanding from others that contributed to these isolating experiences may be based on Holloway et al. (2007) proposition of a 'moral stigma' from health

[18] Interestingly, of all the unsupportive people who contributed to the isolating experience for each participant (e.g. health care professionals, family members, friends, employers, coaches, teammates) only health care professionals were the focus of added frustration and disdain expressed on behalf of the participants (see frustration with medical system – pg 130). This seems to be because CLBP patients expected health care professionals to not only understand their pain, but to provide medical support through pain relief.

care professionals who doubt the physical reality and the legitimacy of persistent CLBP due to an inability to properly identify and diagnose physical causes of pain, which transcends the medical, social, and occupational lives of the patient. However, it is also important to consider the sick role (Frankenberg, 1980). Those participants who expressed bodily suffering to others, but lacked visible physical disability, failed to gain acceptance as "sick" from health care professionals, family members, employers, coworkers, coaches, teammates etc. These same participants were also hesitant to express their suffering given the perceived invalidating response they anticipated from others. Therefore, results from this study reiterate Glenton (2003) suggestion that the sick role concept still appears to reflect the expectations of health care professionals, the public, and even the patients themselves, even though expectations of the sick role are inappropriate for this particular illness. More importantly conforming to expectations of the sick role seemed to perpetuate the isolating experience of CLBP.

Both Frankenberg (1980) sick role and Holloway et al. (2007) 'moral stigma' suggest that when considered physically illegitimate, CLBP can lead to feeling of stigmatization. While a handful of qualitative research supports this notion (Osborn et al. 2006; Holloway et al., 2007; May 2007; Walker et al., 1998), they fail to rigorously investigate the connection of stigmatization with isolation. Furthermore, it is likely that a lack of understanding and a perceived invalidating response from others would only reinforce each participant's reluctance to express their pain, thus, stigmatization may be a mechanism of isolation imposed by others that exacerbates the tendency for self imposed isolation in those with CLBP. However, some

participants expressed the futility in communicating their pain to those without CLBP, as only those with CLBP could share in the understanding of their pain. Previous research has reaffirmed that chronic pain can alienate one from others who do not have pain, as an ethnological study of persons with chronic pain in New England (Jackson, 1994) showed how patients at a pain rehabilitation center experienced a sense of being understood only by fellow pain patients, not by professionals. According to these patients being in a state of chronic pain had no comparable counterpart in experience for people not in pain and in order to understand chronic pain, one had to experience it oneself. Thus, the individualistic and highly personalized nature of CLBP may be the underlying culprit for all forms of isolation (self imposed vs. imposed by others) expressed by participants in this study. Clearly more research on perceptions of pain, stigmatization, fear of anticipated stigmatization, and personal shame, are needed to further articulate the mechanisms in which participants become isolated patients of CLBP. Furthermore, more research focusing on the role of isolation in the CLBP experience would be helpful in further understanding how patients perceive themselves as members in the medical, social, and occupational communities in which they live and the affect this has on quality of life and the perpetuation of long term pain.

**A self concept defined by pain – "Low back pain is a part of who I am"**

Living with CLBP fundamentally altered each participant's self-concept, as all participants expressed the idea that low back pain was a part of who they were and likely would be for the rest of their lives. Although some participants expressed these ideas directly in their interviews, others illustrated this through their description of the

perceived normalcy of pain. In all cases, a continual exposure to CLBP was the culprit for the self-conceptual shift, while in some cases; the perceived inevitability of a future with pain was also a factor. Despite its absence in contemporary systematic reviews on psychological risk factors of CLBP (Linton, 2000; Hasenbring et al., 2001; Pincus et al. 2002; Dunn et al., 2004), the self has been a focus of study in the filed of chronic pain and health in recent years (Aldrich & Eccleston, 2000; Contrada & Ashmore, 1999; Morley & Eccleston, 2004). However, more research on the self and chronic pain, with a focus on the involvement of the body is needed, as psychological pain research has traditionally been criticized for ignoring the body and producing a 'disembodied' account of the experience of pain (Osborn et al., 2006; Kelly et al., 1996).

Bullington's work on the self and embodiment provides a framework that helps to elucidate the process through which participants in this study experienced an altered self-concept. Drawing on the work of the French phenomenologist Maurice Merleau-Ponty, Bullington (2009) analyzed how persons with chronic disease find themselves in a medical praxis that tends to conceptualize their bodies as bodies of the natural sciences or 'objects,' (p. 102) which risks reducing their experiences of chronic disease to medical symptoms. Bullington (2009) argued for an alternative way of conceptualizing ill-health, as when experiencing chronic pain the body no longer "dis-appears" from one's attention (as it does when not in pain) but rather it "dys-appears" appears as "bad" or "ill" (Leder, 1990, p. 85). Thus, the painful body must constantly be attended to and the harmony of the mind–body–world is disrupted, as constant attention to aches and pains diminishes each participant's interest in the

world to only include those aspects that pertain to pain.[19] Furthermore, ubiquitous and constant pain causes the patient's world to become an extension of the pain problem, as pain forces the person to focus on the painful body making it difficult to pay attention to anything else (Bullington, 2009). During times of ILBP the participants focused on pain intensity, uncertainly of pain duration, and pain relief until such pain subsided. During TLBP participants continually focused on their pursuit of a permanent pain consciousness to avoid a recurrence, while all participants felt susceptible to and lived in fear of the perceived consequences of anticipated ILBP. Since the CLBP experience was characterized by persistent TLBP interrupted by periods of ILBP, participants were continually focused on pain and their painful bodies in one way or another, in any and all life situations. This lends support to why participants felt CLBP was such an integral part of their lives. Pain had extended into all aspects of their world and they were continually focused on their pain; therefore pain was their world; pain was their life. Furthermore, when one has become pain and their world is pain, there is little space for their personal self or preferred self (self not defined by pain) (Good, 1992). Therefore, it is no surprise that participants defined themselves as people with CLBP in light of how they use to consider themselves prior to. In this sense, CLBP seemed to reform each participant's self-concept from that of a person to that of a patient. However, participants believed that CLBP would likely be a part of their self-concept for years to come. As Billington (2009) explains, once

[19] Mind, body and world, are actually intertwined and cannot be properly understood apart from one another. It is our way of thinking that divides them, not our experience, as there is no understanding which is not rooted in our embodiment and no body experiences which do not partake of some level of meaning, albeit a rudimentary one (there is mind in body and body in mind). Finally, the human world is, likewise, dependent upon the mind–body harmony in order to show itself as world. For more on this see Merleau-Ponty (1945/1962) and Bullington (2009).

the sense of self has been reduced to pain, it becomes difficult to imagine a future without pain and research has indicated that frustrations with medical management have also been shown to contribute to the idea that pain would persist forever (Campbell et al., 2007). Furthermore, all participants felt susceptible to increased pain and a recurrence of ILBP, which likely further degraded positive outlooks on the future. Therefore, there are various reasons for why participants may have perceived CLBP to be a part of who they likely would be for the rest of their lives.

There is preliminary evidence to suggest that it is just as debilitating to find one's personal sense of self reduced to pain as it is to experience the painful body (Bullington, Nordemar, Nordemar, & Sjo¨stro¨m-Flanagan, 2003; Bullington, Sjo¨stro¨m-Flanagan, & Nordemar, 2005; Lundberg, Styf, & Bullington, 2007). Furthermore, to improve a transformation of the self, people need to be able to experience that their body can be more than a source of pain. When patients begin to experience a new sense of self, a feeling of renewed responsibility for ones' own life will often follow (Bullington et al., 2003; Bullington, 2009) and the utility of retaining a coherent and valued self in chronic pain is associated with improved clinical outcome (Morse, 1997; Norris, Kunes-Connell, & Stockard-Spelic, 1998). Some research has shown CLBP patients to reject their dysfunctional or painful body parts as "not me" (Williams, 2000; Osborn et al., 2006). However, deliberately alienating and excluding the painful body from one's self-concept can potentially impede any constructive process of adjustment or rehabilitation and link chronic pain to emergent negative aspects of the self (Osborn et al., 2006).

Leder's (1990) distinction between the bodily 'dis-appearance' in the absence of pain and the bodily 'dys-appearance' when in pain (whereby the body only enters the consciousness in the event of its dysfunction) was foundational in the progressive development of each participant's self-concept defined by pain. However, the idea that the experience of a persistent and unpleasant pain involves a significant disruption to the usual everyday experience of the body and the emergence of ongoing awareness for the injured body parts (Leder, 1990), helps to illuminate the development of each participant's permanent pain consciousness. All participants tried to be continually aware of their lower backs and all perceived sources of pain during times of TLBP so as to avoid a recurrence of ILBP. This was likely influenced by the 'dys-appearance' of their lower back's following their initial period of ILBP and subsequently the prominence of a new and everyday body which could no longer be taken for granted. However, each participant's permanent pain consciousness was reinforced by their perceived susceptibility to experience an episode of ILBP and their fear of the perceived consequences of such an occurrence. Therefore, while an ongoing and sustained awareness for the lower back and any perceived sources of pain may have been a result of constant dysfunction, susceptibility and fear were also of significant influence. Therefore, the dys-appearance' of the body, perceived susceptibility to pain, and fear of pain consequences seem to all promote the emergence of ongoing awareness for injured body parts. More research is needed on how these three factors interact with one another to promote this on going awareness.

**Somatization**

Only two participants reported medically unexplained somatic symptoms, during times of ILBP (e.g. chest pains) and stories told by the participants gave no indication that somatization was prevalent or of any influence in their experiences of CLBP.

**Study limitations**

Clearly, interpretive phenomenological analysis (IPA) was useful for obtaining vast, rich, and plentiful data on the psychological response to CLBP from the perspective of the patient, as semi-structured interviews helped to elucidate and articulate an in-depth understanding of the CLBP experience. However, the advantages of in-depth, idiographic investigation came at the expense of a limited sample size, as Smith et al. (2003) recommend five to six participants for an interpretive phenomenological investigation at the graduate level; for this study eleven people were interviewed. Since the sample size for this study was small, purposively sampling a heterogeneous group (in reference to age, gender and sick leave) expanded the range of CLBP experiences collectively expressed from the group. Furthermore, two of the participants added to this heterogeneity of pain experiences with their descriptions of lower back surgery. However, all participants in the study were Caucasian Canadians and as Edwards, Fillingim, and Keefe (2001) suggest, racial differences may have an important influence "on how pain is appraised and responded to emotionally and behaviorally (p. 135)." Furthermore, the socioeconomic status of participants was not accounted for and individuals with CLBP of lower socioeconomic status and education are more likely to have increased pain, mental distress and disability (Brekke, Hjortdahl, & Kvien, 2002; Dionne et al.,

2001; Latsa, Kohlmann, Deck, & Raspe 2004). Thus, patient homogeneity in regard to ethnic orientation and a disregard for socioeconomic status limited the range of experiences collectively expressed by the participants and the possibility for new and unique data.

Another sampling concern was that all participants had to confirm their CLBP by indicating that they had experienced LBP in excess of three moths; a classification made clear in van Tulder et al. (2002b) review on LBP. However, results from the study disconfirmed the usefulness of defining CLBP in accordance with duration of pain symptoms. Although a person may be experiencing a single bout of LBP for greater than three months, this could subside shortly after and subsequently be their first and only episode of LBP. As results from this study indicate, CLBP was multiple exacerbations of increased pain within the context of persistent background pain. In hindsight, collecting a history of LBP experiences during the recruitment procedure may have been a more reliable method for confirming the chronicity of their pain. However, varying definitions of CLBP that exist in the literature along with a lack of general consensus over how it develops (Manchikanti et al., 2009) made this a difficult procedure. Fortunately, no participants in this study had experienced CLBP for less than three years and all had experienced multiple recurrences of ILBP, suggesting that they indeed had CLBP.

## Chapter 6 – Conclusion

To experience CLBP was to experience recurring exacerbations of LBP that participants considered unmanageable, uncontrollable and thus intolerable. However, these recurrences took place within the context of a persistent LBP that participants considered manageable, controllable, and thus tolerable. Although each participant experienced persistent TLBP interrupted by recurrent episodes of ILBP, the pattern in which this course of CLBP progressed was different for each individual. Despite the fluctuating, variable and recurrent nature of CLBP, their pain experiences were always either one of two things; tolerable or intolerable. Furthermore, patient reactions to CLBP were specifically related to and contingent upon these varying forms of TLBP and ILBP, in addition to the collective experience of CLBP altogether. Therefore, a clear understanding of the course in which CLBP developed and persisted contributed to an improved understanding for how different psychological factors were involved in the onset and development of such pain. Recurring ILBP contributed to recurring bouts of helplessness, depression, frustration with the medical system and increased fear based on the perceived consequences of anticipated recurrences, all of which were mediated by the uncertainty of pain during such time. Meanwhile, during TLBP all participants felt susceptible to experience a recurrence as they vehemently pursued a permanent pain consciousness in an effort to be forever aware of and avoid all possibilities of a recurrence of ILBP. Finally, as CLBP progressed, participants began to feel as if they were living with a weakness, became isolated from those without CLBP and integrated pain into their self-concept

to represent a part of who they had become and likely would be for the rest of their lives.

Four of the five psychological research themes (depression, catastrophizing, fear-avoidance, anxiety) were significantly involved in these experiences. Depression was a recurring problem during relapses of ILBP that was a result of physical helplessness and an uncertainty for how long the pain would persist. As recurrences became more frequent, previous exposure to increasingly harmful ILBP consequences and each participant's perceived susceptibility to experience increasingly harmful ILBP consequences not yet experienced, were translated into identifiable fears through a process of catastrophizing. Participants continually felt susceptible to experience increasingly harmful ILBP consequences based on the uncertainty of such pain and therefore, were continually catastrophizing exceedingly harmful ILBP consequences that they subsequently lived in fear of. Fear-avoidance, combined with hypervigilance partly characterized the procedures in which participants continually engaged during their pursuit of a permanent pain conscious; including the continual vigilance of bodily movements and the continual anticipation of and preparation for perceived painful stimuli. Fear-avoidance behavior and hypervigilance persisted for as long as participants felt susceptible to a recurrence of ILBP. Anxiety seemed to work with fear of the perceived consequences of anticipated ILBP consequences to cohesively amplify the desire to avoid a recurrence and subsequently reinforce the pursuit of a permanent pain consciousness. However, anxiety seemed to be contingent upon fear, the latter of which was of greater salience to the experience of CLBP.

Finally, somatization was not found to be of any significance in the experiences explicated by the participants.

Therefore, it is clear that interpretive phenomenological analysis (IPA) helped to create an authentic and unique conceptualization of what it means to experience CLBP, which helped facilitate a coherent and clear explication of the psychological response to CLBP in which four of the five psychological research themes were implicated (depression, catastrophizing, fear-avoidance, anxiety). This proves that in order to understand the influence of psychological factors on the onset and development of CLBP and vice versa; one must first understand what CLBP is and how it develops over time. Therefore, it is imperative that future research looks into developing a standard definition of CLBP and a clear conceptualization of how it develops and persists. The success of future research investigating psychological influences on CLBP and vice versa is contingent upon an improved comprehension of CLBP. However, there seems to be an advantage for garnering patient input on how to conceptualize and define CLBP. All participants described a pattern of CLBP that was familiar with contemporary research suggesting the condition to be a recurrent problem of fluctuating pain symptoms. However, their depiction of persistent TLBP interrupted by periods of ILBP added a unique twist, in suggesting that although CLBP was characterized by recurrent and fluctuating symptoms, it was essentially a prolonged interchange of tolerable and intolerable LBP experiences. Therefore, it is clear that patient descriptions of CLBP can be useful for supplementing current ideology on the matter and additional phenomenological investigation dedicated to

understanding the lived experience of CLBP, with a focus on how participants define and describe the course of pain is encouraged.

IPA proved to be a useful supplement to quantitative research on the psychological connection to CLBP. Firstly, four of the five psychological research themes (depression, catastrophizing, fear-avoidance, anxiety, somatization) were presented in a unique way that was meaningful to each participants' experiences of CLBP. Furthermore, patient insights into each of these themes helped to address various shortcomings of the contemporary cross-sectional and prospective research studies in which they were originally derived from. Secondly, IPA provided insight on new and emergent themes, as a permanent pain consciousness, frustration, susceptibility, isolation, uncertainty (although this wasn't a theme per se), and an altered self-concept were all salient features of the CLBP experience not previously accounted for in systematic reviews on the psychological connection to pain. Therefore endorsing IPA was invaluable as it not only advanced current interpretations of well known psychological risk factors made explicit by cross sectional and prospective research on CLBP, but also promoted an increased awareness for unique psychological and intrapersonal problems associated with CLBP underappreciated in clinical studies. Therefore, additional IPA studies focusing on aspects of the psychological response to CLBP previously only studied quantitatively are encouraged. While a review of qualitative studies dedicated to identifying salient features of the psychological response to CLBP not previously accounted for in contemporary quantitative research, would also help to advance knowledge on the psychological connection to CLBP.

After accounting for areas of future research related to specific psychological factors in the discussion, the desperate need for a standard conceptualization of CLBP and the need for future qualitative research on the psychological connection to CLBP, additional specific recommendations for improved management of CLBP must now be addressed. The issue of controllability significantly influenced each participant's response to CLBP. It seemed that when people were able to control and manage their pain (TLBP), they were more apt to positively cope with their condition, than when they perceived pain to be beyond their control (ILBP). However, even when participants felt that pain was tolerable and controllable, they felt as if their susceptibility to experience a recurrence of ILBP was beyond their control and this had a profound influence on their everyday life (e.g. pursuit of a permanent pain consciousness). Therefore, it would be beneficial for health care professionals to facilitate increased feelings of control in patients with CLBP. Even if pain is temporarily incapacitating (ILBP), facilitating a perception of control may at least possibly quell feeling of helplessness, depression, and frustration. Furthermore, increasing perceived control over their ability to avoid a recurrence would significantly help in reducing patient fears and subsequently their hypervigilant and avoidant behavior.

The uncertainty of ILBP significantly influenced each participant's response to such pain. Feelings of depression were partly based on an uncertainty for how long ILBP would persist. An uncertainty for how to manage such pain motivated participants to seek medical help, however, an uncertainty in pain patterns made it exceedingly difficult for health care professionals and patients to establish successful

strategies for managing pain; which subsequently frustrated participants consistently throughout their experiences. Finally, an uncertainty for the severity of the perceived consequences of anticipated ILBP partly contributed to exaggerated negative interpretations of ILBP consequences, which led to increased fear. Therefore, the psychological repercussions of recurring ILBP were established upon a foundation of increased pain but more importantly upon a decrease in pain-related certainty. It would be advantageous for health care professionals to facilitate a professional and ongoing assessment of pain history in addition to encouraging the use of a pain diary on behalf of the patient. This would help to better understand patterns of pain and increase pain-related certainty, so as to improve psychological functioning in those with CLBP.

Finally, it is clear that CLBP has significant psychophysical implications on the patient, as it dramatically alters their everyday lives. The many psychological problems that participants deal with during times of CLBP (e.g. depression, fear, isolation, altered self-concept etc) make the CLBP experience a highly individualistic experience. This of course makes CLBP a very difficult condition to manage as health care professionals and researchers alike have to recognize and address CLBP as a condition that disrupts one's life situation, in addition to one's body. Health care professionals specifically need to manage CLBP with a client-centered rather than pain-centered approach. However, in order to do so both parties need to work harder at better understanding each others needs. When health care professionals endorse biomedical traditions to rehabilitation and focus on pain centered, rather than patient centered interventions (e.g. the power of the body to heal itself), they tend to objectify

the bodies of those who are ill and fail to account for unique individual experiences associated with CLBP. However, if patients expect immediate relief of pain than this reinforces tendencies of health care professionals to treat their bodies as objects in need of "fixing." Thus health care professionals and patients need to better understand each others needs and expectations to help facilitate improved clinical outcomes.

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## Chapter 8 – Data Manual

### Section A

### Research Ethics Board Letter of Approval

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Brock University
Office of Research Services
Research Ethics Office
St. Catharines, Ontario, Canada L2S 3A1
T: 905-688-5550, Ext. 3035/4876 F: 905-688-0748

| | |
|---|---|
| DATE: | 12/12/2008 |
| FROM: | Michelle McGinn, Chair<br>Research Ethics Board (REB) |
| TO: | Jarold Cosby, Physical Education & Kinesiology<br>Matt Aymar, Maureen Connolly, Dave Ditor |
| FILE: | 08-119 COSBY/AYMAR<br>Masters Thesis/Project |

**TITLE:** A phenomenological approach to understanding the psychological response to chronic low back pain

The Brock University Research Ethics Board has reviewed the above research proposal.
DECISION: **Accepted as Clarified**

This project has received ethics clearance for the period of December 12, 2008 to September 30, 2009 subject to full REB ratification at the Research Ethics Board's next scheduled meeting. The clearance period may be extended upon request. The study may now proceed.

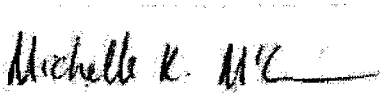
Please note that the Research Ethics Board (REB) requires that you adhere to the protocol as last reviewed and cleared by the REB. During the course of research no deviations from, or changes to, the protocol, recruitment, or consent form may be initiated without prior written clearance from the REB. The Board must provide clearance for any modifications before they can be implemented. If you wish to modify your research project, please refer to http://www.brocku.ca/research/policies-andforms/forms to complete the appropriate form Revision or Modification to an Ongoing Application.

Adverse or unexpected events must be reported to the REB as soon as possible with an indication of how these events affect, in the view of the Principal Investigator, the safety of the participants and the continuation of the protocol.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research protocols.

The Tri-Council Policy Statement requires that ongoing research be monitored. A Final Report is required for all projects upon completion of the project. Researchers with projects lasting more than one year are required to submit a Continuing Review Report annually. The Office of Research Services will contact you when this form Continuing Review/Final Report is required.

Please quote your REB file number in all future correspondence.
MM/kw



## Section B

## Telephone Communication Script Number One

P = Potential Participant; I = Interviewer

I – May I please speak to [name of potential participant]?

P – Hello, [name of potential participant] speaking. How may I help you?

I – My name is Matt Aymar and I am a Masters student in the Faculty of Applied Health Sciences at the Brock University. I am currently conducting research under the supervision of Dr. Jarold Cosby on chronic low back pain. (If they were referred by another person) I recently received your telephone number from (say name of contact). Would you be interested in learning more about the study?

P – No. (Thank them for their time and wish them goodbye)

OR

P – Yes

I – Excellent, as part of my thesis research, I am conducting interviews with people experiencing chronic low back pain to help discover their views on the chronic low back pain experience. Therefore, the purpose of this study is to learn about how people deal with their chronic low back pain. Before we proceed any further, I need to ask a few quick questions to verify specific demographic factors; are you male or female? (P answers) Which of the following age ranges do you fit into; 20 to 30, 30 to 40, 40 to 50, 50 to 60, or 60 +? (P answers) How long have you had low back pain? (P answers) Have you ever taken at least seven consecutive days off of work due to your low back pain? (P answers) Thank you.

(If P does not fit required demographics) Unfortunately, we require specific types of participants and you do not meet the requirements to participate in this study. I apologize for this inconvenience and thank you for your time. Goodbye.

OR

(If P does fit required demographics). Excellent, I would like to speak with you about your chronic low back pain experience. Is this a convenient time to give you further information about the interviews?

P – No, could you call back later (agree on a more convenient time to call person back).

OR

P – Yes, could you provide me with some more information regarding the interviews you will be conducting?

I – Ok, here is some background Information:

- I will be undertaking interviews starting this winter.

- The interviews will be conducted in the Health Decisions Lab at Brock University located on 500 Glenridge Avenue in St. Catharines, ON, Canada.

- The interview will last approximately forty-five minutes to one hour and would be arranged for a time convenient to your schedule.

- Involvement in this interview is completely voluntary and you can choose to withdraw at any time.

- The interview questions are quite general (for example, Do you recall the time when you first started complaining of low back pain?). Interview questions will also be open ended to allow for detailed answers and semi structured around critical events of the chronic low back pain experience and the psychological connection to pain.

- You may decline to answer any of the interview questions you do not wish to answer and may terminate the interview at any time.

- With your permission, the interview will be audio digitally recorded to facilitate collection of information, and later transcribed for analysis.

- All information you provide will be considered confidential.

- Two weeks after the study has been completed you will be mailed a one page summary of the research results.

- The data collected will be kept in a secure location and disposed of by September 2009.

- With your permission, I would like to mail or email you an information package which has all of these details along with contact names and numbers on it to help assist you in making a decision about your participation in this study.

P – No thank you, I am not interested. (Thank them for their time and wish them goodbye)

OR

P – Sure (decide on method of mailing and obtain contact information from potential participant i.e., mailing address or email address).

I – Thank you very much!

- If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please feel free to contact Dr. Jarold Cosby at 905-688-5550 Ext. 5340

- I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics. However, the final decision about participation is yours. Should you have any comments or concerns resulting from your participation in this study, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)

- I will call you in 3 to 5 days to see if you are interested (or still interested) in being interviewed. Thank you very much for your time. Once again, if you have any questions or concerns please do not hesitate to contact me by phone at 905-688-5550 ext 5340 or by email at ma03nu@brocku.ca

P – Good-bye.

I – Good-bye

**Section C**

**LETTER OF INVITATION**

January 2009

**Title of Study:** Telling your low back pain story

**Principal Student Investigator:** Matthew Aymar, Graduate Student, Department of Applied Health Sciences, Brock University

**Faculty Supervisor:** Dr. Jarold Cosby, Assistant Professor, Department of Applied Health Sciences, Brock University

Brock University's Health Decisions Lab would like to invite you to participate in a research project about chronic low back pain. The purpose of this research project is to give you an opportunity to share your low back pain story.

I will be conducting in-person interviews with a selection of volunteers in an attempt to understand the impact of low back pain on your work, your life, your hobbies, and your family.

The interview will last approximately 45 minutes.

Your participation will provide data that will help contribute to an improved understanding of chronic low back pain. This will help us improve our success with diagnosing, managing, and treating chronic pain in the future.

This is a single-sited project as all interviews will be conducted at Brock University, at 500 Glenridge Avenue, in St. Catharines, ON, Canada. Your involvement in this study is strictly voluntary and you have the right to refuse participation at any time. Upon completing your interview you will be compensated for any parking fees you may incur.

Please read the informed consent form for more information regarding the risks and benefits of participating in the study, the feedback you are entitled to receive as a participant, and the procedures to ensure the confidentiality of your participation in the study. If you have any further questions regarding the study feel free to contact Dr. Cosby or me at a time convenient for you.

If you have any questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)

Thank you
Sincerely,

Matthew Aymar
Graduate Student
905-935-8874
ma03nu@brocku.ca

Dr. Jarold Cosby
Assistant Professor
905-688-5555 ext 5340
jcosby@brocku.ca

This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (08-119 COSBY/AYMAR)

## Section D

## Informed Consent Form

Date: January 2009
Project Title: Telling your low back pain story

Principal Student Investigator:
Matt Aymar, Graduate Student
Faculty of Applied Health Sciences
Brock University
(905) 935-8874; ma03nu@brocku.ca

Faculty Supervisor:
Jarold Cosby; Professor
Faculty of Applied Health Sciences
Brock University
(905) 688-5550 Ext. 5340; jcosby@brocku.ca

### INVITATION

Brock University's Health Decisions Lab would like to invite you to participate in a research project about chronic low back pain. The purpose of this research project is to give you an opportunity to share your low back pain story.

### WHAT'S INVOLVED

As a participant, you will be asked to complete an interview with the researcher. Interviews will be audio digitally recorded and transcribed verbatim. Interviews will be one on one and conducted at Brock University on 500 Glenridge Avenue, in St. Catharines, ON, Canada. Interviews will focus on your experiences with chronic low back pain, specifically on the psychological response to pain. Questions will be semi-structured around "critical events" of the chronic low back pain experience (e.g. when you first injured your back, when you first received treatment etc). Altogether the interview is an exciting chance for you to share your story. Participation will take approximately 45 minutes of your time in addition to travel time to from and the interview. Only one interview is required.

### POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include the opportunity to tell your chronic low back pain story, the opportunity to see an interpretation of the meaning of your experiences and to understand your experiences in relation to other chronic low back pain participants. You also will contribute to an improved understanding of the psychological connection to chronic low back pain, thus, increasing the opportunity for improved success with diagnosing, managing, and treating chronic low back pain. There also may be risks associated with participation as reflecting on troublesome experiences may result in increased feelings of emotional stress. However, you are given the opportunity to avoid answering any questions you feel uncomfortable with. Furthermore, the principal student investigator has formal training in qualitative interviewing and responding to chronic pain and is well prepared to manage such risks.

For your information, here are a few academic and professional resources that discuss chronic low back pain. The American Chronic Pain Association (http://www.theacpa.org/default.asp) is a website dedicated to facilitating peer support and education for individuals with chronic pain, while a list of local support groups and an opportunity to connect with others suffering from chronic pain are available on the Chronic Pain Association of Canada website at (http://www.chronicpaincanada.com/).

For a more advanced and informative inquiry you may wish to seek out "Managing Chronic Pain: A Biopsychosocial Approach" by Saxi Pridmore[20] . This is a scholarly and practical patient centered book with practical guidance for managing the psychosocial aspect of chronic pain.

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[20] Pridmore, S. (2002). *Managing chronic pain: A biopsychosocial approach.* Philadelphia, PA: Taylor & Francis, Inc

Finally, the Canadian Back Institute is a privately-owned leading Canadian healthcare service and management company dedicated to providing an integrated approach to health management. They offer a variety of professional services and expertise for people with low back pain and have a clinic located in Niagara Falls, ON (CBI Niagara Falls) at 4256 Portage road (905 374-1133 fax: 905 374-7631). For more information you can visit their website at (http://www.cbi.ca/default.htm)

**CONFIDENTIALITY**

The information you provide will be kept confidential. Your name will not appear in any thesis or report resulting from this study; however, anonymous quotations may be used. The anonymity of participants both during the conduct of the research and in the release of its findings will be secured through the use of encoded numbers and pseudonyms. Data collected during this study will be stored in a desk drawer which will be secured by lock and key and electronically on a computer hard drive, which will be secured by user name and password. Data will be retained until the completion of the project after which time all hard copies of data will be shredded and all electronic copies of data will be erased. Access to this data will be restricted to Matthew Aymar (principal student investigator) and Dr. Jarold Cosby (faculty supervisor). However, if you wish to access you interview transcript, you can do so by contacting either Matthew Aymar or Dr. Jarold Cosby via telephone or email. All requested transcripts will be delivered within twenty-four to forty-eight hours of the request, however all interview transcripts will be destroyed and subsequently no longer available for request after the study has been completed. The estimated time of completion for this study is 01/09/09.

**VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which you are entitled. To withdraw from the study you must contact the principal student investigator via telephone or email before the study has been completed and submitted for publication or for presentation at conferences. After the study has been submitted for publication you will no longer be able to withdraw your data from the study. The estimated time of completion and submission for publication is 01/09/09.

**PUBLICATION OF RESULTS**

Results of this study may be published in professional journals and presented at conferences. A one page summary of the results will be mailed to all participants two weeks after the study has been completed. You are also entitled to view a full length copy of the thesis and may do so by requesting a copy from either the principal student investigator or principal investigator via telephone or email. All academic papers will be mailed within one week of the request.

**CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions about this study or require further information, please contact the principal investigator or the faculty supervisor using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University (08-119 COSBY/AYMAR). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca. Thank you for your assistance in this project. Please keep a copy of this form for your records

**CONSENT FORM**

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____

Signature: _____ Date: _____

## Section E

## Telephone Communication Script Number Two

P – Potential Participant; I – Interviewer

I – May I please speak to [name of potential participant]?

P – Hello, [name of potential participant] speaking. How may I help you?

I – Hi, this Matthew Aymar from the Health Decisions Lab at Brock University. I am calling to confirm that you reviewed the forms I emailed you and that you are still interested in participating in the study?

P – No I am not (thank them for their time and wish them goodbye)

OR

P – Yes I am

I – Excellent (agree on an interview time) I will email you a confirmation letter which will provide you with directions to Brock University, where on Campus the interviews will be conducted, where you can find parking, the time and date of the interview, as well as a cell phone number you can contact me with.

I would like to remind you once more that participation in this study is strictly voluntary and it is your right as a research participant to withdraw from the study at any time without penalty. Also, the information you provide will be kept confidential. Your name will not appear in any thesis or report resulting from this study; however, anonymous quotations may be used. The anonymity of your participation both during the conduct of the research and in the release of its findings will be secured through the use of encoded numbers and pseudonyms.

Finally, I would like you to confirm that you have agreed to participate in the study as described in the informed consent form and that you have made this decision based on the information you have read in the Information-Consent Letter. Also I would like you to confirm that you have had the opportunity to receive any additional details about the study and understand that you may ask questions in the future and may withdraw this consent at any time up until the point of publication.

Can you confirm these details?

P – No I cannot (inform them that they cannot participate in the study until they can confirm these details and arrange for them to contact you via email or telephone when they can confirm these details)

OR

P – Yes I can.

I – Excellent, you will be receiving your confirmation letter shortly via email. Good bye.

P- Good bye.

## Section F

## Confirmation Letter

Day/Month/Year

Dear (name of participant),

This letter is to remind you of your interview on low back pain at Brock University on (date/time of interview).

The interview will take place in the Health Decisions Lab located in Welch Hall, room number WH 145.

Parking will be provided in Visitor Parking (Lot D) near the Walker Complex. Please call me at 289-241-8432 when you arrive on campus and I will come meet you in parking lot D or the Walker Complex Café, whichever you prefer.

Brock University is located on 500 Glenridge Avenue, St. Catharines, ON. Use this information to find exact directions to the campus through www.mapquest.com.

You are asked to be on campus fifteen minutes before your interview time. If at any time you get lost and cannot find parking lot D than please call me at 289-241-8432. For an easy way to find parking lot D please refer to the Brock University Campus Map I have provided for you.

I would like to take this opportunity to once again remind you that your participation in this study is strictly voluntary and you have the right to withdraw from the study at any time without penalty.

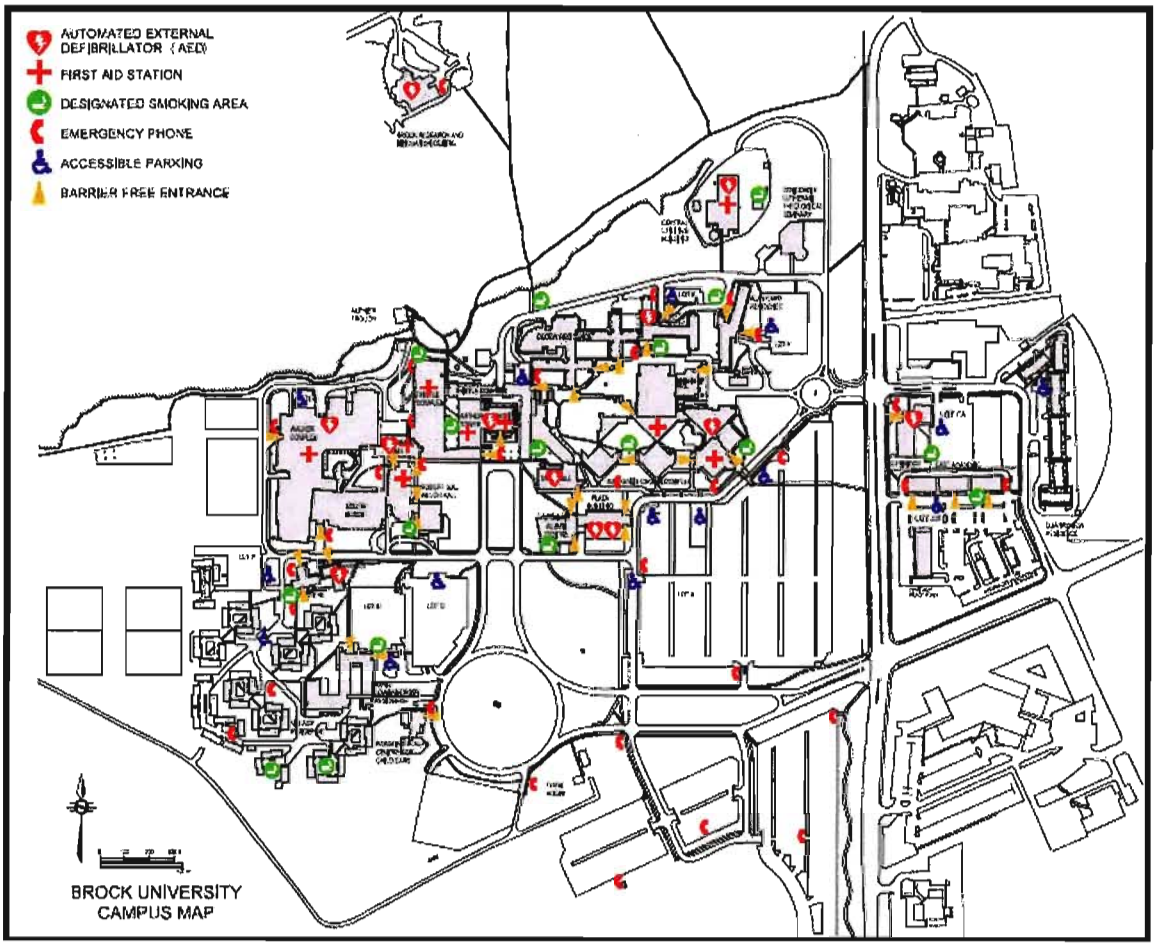
Finally, I want to thank you for your cooperation and for volunteering your time.

I am looking forward to our interview,

Sincerely,
Matthew Aymar.

## Section G

## Brock University Campus Map



## Section H

## Telephone Communication Script Number Three

P – Potential Participant; I – Interviewer

I – May I please speak to [name of potential participant]?

P – Hello, [name of potential participant] speaking. How may I help you?

I – Hi, this Matthew Aymar from the Health Decisions Lab at Brock University. I regret to inform you that all positions to participate in the study on chronic low back pain have been filled. However, additional volunteers may be called upon in the event that a participant withdraws from the study before or after their designated interview time. Would you like me to contact you if another participation position becomes available?

P – No thank you (thank them for their time and wish them goodbye).

OR

P – Yes I would.

I – Excellent, I want to thank you for your time and consideration. I will contact you in the event that a participant withdraws from the study. This may be any time between now and next summer. Goodbye.

P – Goodbye.

## Section I

### Uncertainty of pain – The torture metaphor

Experiences from this study suggest that uncertainty in which ILBP persisted, as oppose to the severe and debilitating pain itself, directly contributed to psychological forms of distress. To further understand how, consider the notion of torture. What makes it so gruesome is the uncertainty of what comes next. For example, in the independent film and cult classic *Reservoir Dogs* (Bender, 1992), there is a scene where Mr. Blonde (Michael Madison) tortures a police officer, as he ties him up and slowly torments the cop with physical abuse that is increasingly more painful. One would think the grotesquely violent, physical abuse would be the most difficult aspect of the torture experience. But now consider the many uncertainties from the perspective of the police officer during this horrific scene; is he going to shoot me!? Will he cut off any other appendages!? Is he going to set me on fire!? I am going to die!? What about my kids!? How far is he willing to take this!? How long with this go on for!? In this case, the fear of the unknown was likely greater than the fear of pain. Now consider the story of the Greek Titan Prometheus. He gave fire to man, so Zeus tied him to a rock and had an eagle eat his liver everyday, only to have it regenerate each night (Vadakethu, 2004). Everyday Prometheus knew what was coming, when it was coming, and how long it would take to recover. Therefore, although both examples of torture were equally gruesome and extremely painful (pain is relative here!), the victims' experiences were considerably different due to pain related certainty. Now consider the case of Jacob. He was the only participant to experience pain related certainty (albeit temporarily) during recurrences of ILBP. He

experienced a number of recurring bouts with ILBP that were similar in nature and lasted no more than six weeks, with or without intervention. This certainty of pain helped him positively cope with and manage his recurrences. However, when Jacob experienced a recurrence of longer duration and with greater pain consequences than ever before, a sense of uncertainty negatively affected Jacob's ability to cope with such pain. Therefore, uncertainty of pain can profoundly affect one's ability to cope with two episodes of equally debilitating ILBP and according to Jacob; the uncertainty of pain is perhaps one of the most mentally challenging aspects of the CLBP experience:

> *"I think if people knew where the end was, they would gut their way through and do what they had to do to get there but not knowing, uh....in life, its a lot of things. Not knowing is the real killer on our minds and in our approach to things (10; 13; 9)."*